# making the CIRCLE BIGGER

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## South African Higher Education, Social Justice & Students with Disabilities

Edited by

**Desire Chiwandire & Louise Vincent**

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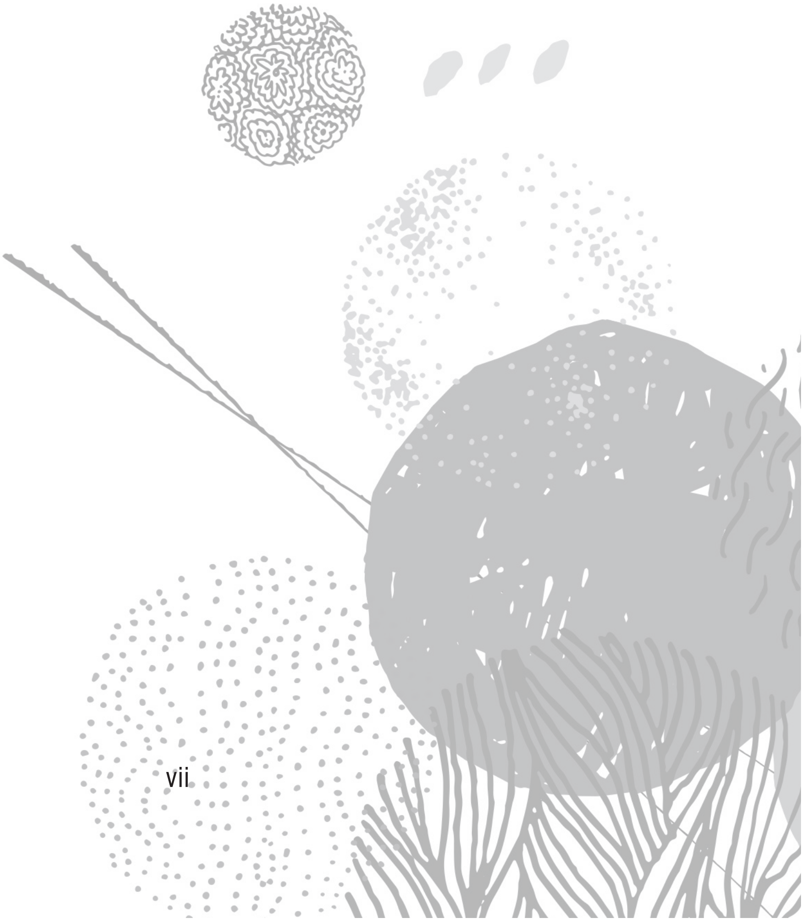

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# Foreword

“Students with disabilities make up less than 1% of South African students, which is shocking both because at least 5% of young people have disabilities, but also because education is the key to economic inclusion for disabled people, who may not be able to take up manual occupations. Transforming tertiary education is one route to transforming society. This scholarly and above all useful book shares both experiences and advice on how to get there.”

*Tom Shakespeare CBE, Professor of Disability Research, LSHTM*

# Contributors

## Editors

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**Prof Sindile Amina Ngubane** is a Full Professor specialising on Information and Communication Technology Access and Disability research in higher education. She is also the Head of Department for the Institute for Open and Distance Learning at University of South Africa (Unisa). She is the former Deputy Director at the Advocacy and Resource Centre for Students with Disabilities, Curriculum Transformation Specialist in the Curriculum Transformation Unit, and Deputy Chairperson of Unisa Women's Forum. She has published academic papers, book chapters, presented at international and national conferences and supervised masters and doctoral students to completion. In addition, Prof Ngubane leads Cross-border collaborative research and community engagement projects which aim at creating inclusive approaches to the development of vulnerable communities which include people with disabilities, women with and without disabilities, children and the elderly. Ngubane is also leading a community project called MarginsToTheCentre which provides support for people in the margins with an aim of creating sustainable and safe communities.

## Artist

**Felix Chiwandire**. Cover Image painted by Felix Chiwandire 'Inclusivity', Artwork by Felix, September 2021.

# Abbreviations

| | |
|---|---|
| ANC | African National Congress |
| ARCSWiD | Advocacy and Resource Centre for Students with Disabilities |
| CCRF | Canadian Charter of Rights and Freedoms |
| CHRA | Canadian Human Rights Act |
| CIQ | Critical Incident Questionnaire |
| CSGSESPD | Canada Student Grant for Services and Equipment for Students with Permanent Disabilities |
| CTL | Centre for Teaching and Learning |
| CUADS | Centre for Universal Access and Disability Support |
| DHET | Department of Higher Education and Training |
| DISA | Department of Institutional Statistics and Analysis |
| DSA | Disabled Students' Allowance |
| DSD | Department of Social Development |
| DSP | Disability Support Program |
| DUSMs | Disability Unit Staff Members |
| EA | Equality Act |
| EDIR | Equality and Diversity Interim Report |
| ES | Equality Scheme |
| EU | European Union |
| FOTIM | Foundation of Tertiary Institutions of the Northern Metropolis |
| HE | Higher Education |
| HECFE | Higher Education Funding Council for England |
| HEMIS | Higher Education Management Information System |

| | |
|---|---|
| HESPN | Higher Education for Persons with Special Needs |
| HSRC | Human Sciences Research Council |
| IPC | International Paralympic Committee |
| NP | National Party |
| NPHE | National Plan for Higher Education |
| NSFAS | National Student Financial Aid Scheme |
| NUS | National Union of Students |
| OCD | Obsessive-Compulsive Disorder |
| ODL | Open distance learning |
| OECD | Organisation for Economic Co-operation and Development |
| PALAR | Participatory Action Learning and Action Research |
| PWD | Protection of Rights and Full Participation (PWD) Act |
| RAs | Reasonable Accommodations |
| SRC | Student Representative Council |
| SSA | Specials Schools Act |
| TEFSA | Tertiary Education Fund of South Africa |
| TUT | Tshwane University of Technology |
| UDL | Universal Design for Learning |
| UN | United Nations |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |
| UNESCO | United Nations Educational, Scientific and Cultural Organisation |
| UNISA | University of South Africa |
| WHO | World Health Organisation |

# Chapter 1

## INTRODUCTION

### Desire Chiwandire and Louise Vincent

In apartheid South Africa, access to higher education (HE) was a privilege reserved largely for the minority white population at the cost of the majority black population. The National Party government's policies of racial segregation and highly unequal allocation of resources were deliberately aimed at preventing the intellectual development, providing of opportunities, and economic advancement of black citizens (Fletcher and Zuber-Skerritt 2008; Shrivastava and Shrivastava 2014). Black learners with disabilities were particularly low on the priority list of the National Party government (Fagin 2011), with the Special Schools Act (SSA) in 1948 providing for a segregated education system which categorised children with disabilities according both race and disability (Muthukrishna and Schoeman 2000), making it especially difficult for learners with disabilities to access HE.

With the advent of democracy in 1994 came a new constitution, the preamble of which states the intention to 'hal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights … [and to] improve the quality of life of all citizens and free the potential of each person'. It was in this context that the post-apartheid African National Congress (ANC) government set about enacting policies aimed at 'putting in place appropriate redress strategies for the past inequities of the apartheid era.' (Mapesela and Hay 2005, 112 see also Akoojee and Nkomo 2007). The HE sector has been no exception. The democratic era has seen an array of policy measures put in place to remove barriers to access HE for those who had been systematically excluded as a result of apartheid policies (Badat 2010; Mapesela and Hay 2005; Roebken 2008; Belyakov et al. 2008). Although the focus has been on racial redress, students with disabilities have been included in these measures from the outset—see, for example, White Paper 3 on Higher Education Transformation (1997); the White Paper on an Integrated National Disability Strategy(1997); the Higher Education Act (1997); the National Plan for Higher Education (2001); the Education White Paper 6

(2001), Special Needs Education: Building an Inclusive Education and Training System; and the Strategic Policy Framework on Disability for the Post-School Education and Training System (2018)—all of which emphasise the need to address the disadvantages that persons with disabilities experienced in the past and to prioritise funding of HE opportunities for students with disabilities. Indeed, some have applauded these policies as 'the best in the world, meeting internationally acclaimed standards' (Mapesela and Hay 2005, 112).

Since the early 1990s, the approach has not only been to support increasing and broadening access to university for previously disadvantaged groups, but also the promotion of social justice in the system (Wilson-Strydom 2011). Legislative initiatives have been aimed not merely at inclusion, but also at transforming the entire HE system (Mapesela and Hay 2005; see also Pandor 2005). White Paper 3 and the Report of the Ministerial Committee on Transformation and Social Cohesion and the Elimination of Discrimination in Public Higher Education Institutions (otherwise known as the Soudien Report 2008) in particular highlighted the immediate need of higher education institutions (HEIs) to transform their structures, practices and cultures if they are 'to promote a sense of belonging and comfort for various individuals who come into contact with these institutions' (Munyuki 2015, 129). The notion of 'access with participation' summed up the goal of not only promoting access for those previously excluded from participation in higher education but going beyond access to promote equal participation (Belyakov et al. 2008). The South African government's prioritisation of increasing student access to HE in the early 1990s was, moreover, taking place in a wider context of global calls for greater access—see, for instance, the call for 'equality of access' at the UNESCO World Conference on Higher Education in 1998 (cited in Akoojee and Nkomo 2007, 385).

Financing equality of access has always been acknowledged to be a key component of successful HE transformation (Akoojee and Nkomo 2007) The National Student Financial Aid Scheme (NSFAS), a student loan scheme, was established in 1996 to fund access to HE for needy but capable students (Carrim and Wangenge-Ouma 2012). NSFAS aims at 'ensuring that access to higher education is facilitated by offering loans to disadvantaged students provided that students meet the entrance criteria of institutions' (Cele and Menon 2006, 43). In 2017, the Minister of Higher Education and Training Blade Nzimande argued that 'since its inception as the Tertiary Education Fund of South Africa (TEFSA) in 1991, NSFAS has awarded about R72 billion in loans and bursaries' (Minister Nzimande cited in Ndlendele 2017). The availability of NSFAS funding has played an important role in increasing the numbers of disadvantaged black students accessing HEIs (Pityana 2006). For example, research conducted by Cooper and Subotzky's (2001; see also Pityana 2006) concluded that South Africa has experienced a revolution in relation to the increase in the proportion of black students in HE. The ratio of black students in total university enrolment increased from 32 per cent in 1990 to 60 per cent in 2000 while technikon enrolments rose from 32 per cent to 72 per cent over the same period (Cooper and Subotzky 2001). Thus, by 2000, African students formed the majority in both universities (60%) and technikons (72%) (Cooper and Subotzky 2001). As Cloete (2002) has remarked, these demographic changes must be amongst the most remarkable in the world during the 1990s.

Between 1999 and 2003, first entry students at South Africa's 21 public universities and 15 technikons increased from 131 000 to 182 000 with the total headcount increasing by some 25 per cent—from 540 000 to 718 000 (Department of Education, 2005). Through its new National Plan for Higher Education (NPHE), the state signalled that there would be no letting up on the pressure on universities to swell the HE participation rate from 1per cent to 20 per cent given the critical shortage of skilled labour to promote development (Ministry of Education 2001).

However, critics have warned that these statistics do not necessarily mean that the South African HE sector 'is performing well in terms of both increasing and broadening university access and that social justice gains have been made' (Wilson-Strydom 2011, 407). White Paper 3 of 1997 enjoined institutions to ensure that equity of access is 'complemented by a concern for equity of outcomes'. Increased access must not lead to a 'revolving door' syndrome for students, with high failure and dropout rates' (DoE 1997, 22). In practice, institutions have struggled with high rates of student dropout, low throughput rates, and low graduation rates (Cele and Meno 2006).

The cost has been high with government reportedly losing approximately R4,5 million in subsidy paid to HEIs (half of the actual subsidy paid) as a result of student dropout between 2000 and 2003 (Cele and Meno 2006). Some 30 per cent of students enrolled at the beginning of 2000 had dropped out by the end of that year and a further 20 per cent by the end of 2002. Out of the 50 per cent of students remaining in the system, less than half graduated in the minimum requisite time allocated for their degrees (Cele and Meno 2006). It is estimated that, on average, some 25 per cent of students, mainly from low income households, are annually excluded from HEIs on academic and financial grounds (Koen et al. 2006).

The 2007 Student Pathways study conducted by the Human Sciences Research Council (HSRC) found that, on average, only 15 per cent of South African students finish their degrees in the allotted time (Macgregor 2007) and that 'a shocking 40 per cent of South African students drop out of university in their first year'. Many of those who drop out are black first-generation students from low-income, less educated families and financial difficulties are often the cause, NSFAS notwithstanding (Macgregor 2007). As critics have argued, being a NSFAS recipient may provide someone with access to university but has little impact on success rates as 'loans and bursaries do not cover the full costs of study, leaving poor students struggling to meet living and other expenses' (Macgregor 2007). Other reasons for unfavourable completion rates include inadequate human resources with faculty numbers at universities and other resources and infrastructure having failed to keep up with increasing student enrolments (Machika 2013).

Whilst an enabling legislative environment and the NSFAS scheme's financial support have seen improved access to HE, especially for disadvantaged black students, the academic success of these students has been, and continues to be, a daunting challenge. What is more, success in relation to the increasing percentage of black students in HEIs can serve to obscure 'institutions' inability to interrogate transformation itself' (Lange 2014, 4). In other words, rather than merely promoting access there is a need to ask difficult questions about the environment to which we are promoting access. Students who are NSFAS recipients enter HEIs 'with high expectations of success based on their matriculation results but then become despondent as they experience academic failure'

(Machika 2013, 92), cultivating, as Wilson-Strydom (2011, 407) has noted, ‘a new form of social exclusion’.

These concerns have necessitated a shift in emphasis to the promotion not just of access but of ‘access with success’ (Belyakov et al. 2008, 1). The NPHE, for instance, refers to ‘fair opportunities both to enter higher education programmes and to succeed in them’ (Ministry of Education 2001; 2001). The White Paper for Post-school Education and Training highlights the need for HEIs to prioritise improving performance, access, success, and throughput rates, particularly ‘for those groups whose race, gender and disability status had previously disadvantaged them’ (DHET 2013, 7). The Minister of Higher Education and Training Blade Nzimande has frequently invoked the mantra of access with success, referring, for example, in 2013 to ‘our vision of a South Africa in which we have a differentiated and fully inclusive post-school system that allows all South Africans to access and succeed in relevant post-school education and training’ (Parliamentary Monitoring Group 2013), and, in 2015, noting the DHET’s commitment to ‘expanding access and success in institutions of higher learning for students who have special needs’ (*SA News* 2015).

The unprecedented broadening of access initiatives of the 1990s propelled the massive enrolment at South African universities of underprepared students who had gone through inadequate schooling systems and were ill-equipped to succeed at university (National Planning Commission 2011; Koen et al. 2006). As a result, some have argued, ‘traditional teaching methods have become unsuitable for enabling the underprepared student to meet the educational demands of the late 20th and early 21st century’ (Knapper 2003, 6). The DHET (2013, 5) has suggested that a key measure for improving success rates is ‘strengthening learning and teaching across the system’. This diagnosis of the problem as being one of underprepared students led to academic inclusion-oriented solutions, such as the establishment of academic development programmes aimed at supporting these underprepared students (National Planning Commission 2011). As an example, the University of South Africa (Unisa) devised a R50 million project establishing a network of tutors and academic support personnel (Macgregor 2007).

Others have focused more on the financial causes of high student dropout rates, particularly on the inadequacy of NSFAS loans (Macgregor 2007), on management and the efficiency and quality of services (Palihawadana 1999), and the need for institutions to make effective planning interventions based on a better understanding of students and their needs (Subotzky and Prinsloo 2011). What all these approaches have in common is that student success has come to be understood as the responsibility not just of students themselves, but also of institutions and their staff who have a responsibility to play an active role in making HEIs conducive environments in which all have an equal opportunity to succeed (Engstrom and Tinto 2008). As scholars have illustrated, an education system that is devised to meet the needs of *all* students is a question of justice (see for example Mafumo 2011).

However, while the shift from a focus on access to critical attention to questions of outcomes or success has been valuable and necessary, the particular challenges faced by students with disabilities with respect to both access and success have not always received the same attention as other forms of exclusion, such as those based on race and gender. Rather, students with disabilities have sometimes been treated as an afterthought in South

Africa's HE transformation initiatives (Higbee 2003). As Lange argued in *Rethinking Transformation and Its Knowledge(s): The Case of South African Higher Education*, 'transformation' of HE has often been narrowly conceived in ways that perpetuate the exclusion of students with disabilities:

> Transformation has been reduced to the numbers, percentages and ratios of black and white people and, to a lesser extent, men and women involved in or accepted into institutions, professions, positions, education, etc. Very few, if any, other variables like class, sexual orientation, and disability make it into the statistical cut, and the overall orientation of institutions and policies tends to fall under the radar of a more nuanced sense of transformation (Lange 2014, 4).

In the same way that the promotion of access without attention to the conditions of success proved inadequate and led to new problems of high rates of attrition, attention needs to be paid not just the participation rates, but also the conditions for attainment of students with disabilities as an acutely historically marginalised group (Ainscow 2006; see also WHO 2011).

Inclusive education, as Ainscow et al. (2004; see also Ainscow 2006; Mittler 2000) have argued, is not only a basic human right, but more importantly, is the foundation for a more just society. The right to inclusive education is protected by international human rights instruments such as the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)—to which South Africa is a signatory. Moreover, section 29(1)(a) of the Constitution of South Africa guarantees everyone (including persons with disabilities) the right to education, and prohibits the state from unfairly discriminating 'directly or indirectly against anyone on the grounds of disability' (Section 9(3) among other grounds). The World Health Organisation (WHO) has argued that HEIs have a moral obligation to provide quality education that meets the basic learning needs and enriches the lives of students with disabilities (WHO 2011). Moreover, as was seen in the case of measures to include other historically marginalised groups, the point is not to seek inclusion into an untransformed system (Slee 2001), but to address ways in which the system needs to change to be able to cater to the needs of all.

Many universities still do not have facilities to cater for students with disabilities, and in a number of prominent recent cases applicants have been denied access to universities on the grounds that they could not be 'accommodated'. Even when access is not denied outright, students with disabilities face multiple attitudinal and other institutional barriers to being able to thrive and succeed at South African universities. The experiences of students with disabilities alert us to the ways in which, in post-apartheid South Africa, social institutions continue to preach 'inclusion' without asking the central question: included into what, and by whom? Inclusion into untransformed cultures, physical environments and day-to-day practices does not make institutions more just.

In reality, and perhaps unsurprisingly, given the apartheid past, inclusion initiatives in South Africa's HE system have often focused on class, race and, to some extent, gender (Shrivastava and Shrivastava 2014)—see, for instance, Mafumo's argument that South African HEIs could be said to be achieving social justice if they equitably 'meet the needs of all students irrespective of their race, sex, financial background [or class]'(2011, 1554). The principle instrument to address class and racial exclusion has been NSFAS, with impressive results from the point of view of sheer access—black students from poor backgrounds constituted 75 per cent of total enrolments by 2003 (Koen et al. 2006). This gender discrepancy was clearly evidenced by the statistics from the 2001 South African census which showed that 3.1 per cent of disabled males as compared to the 2.9 per cent of females with disabilities had access to HEIs (Stats SA 2005).

Whilst in existing approaches there has been some acknowledgement of the intersectionality (see Crenshaw 1989) of exclusion—and hence of the need for approaches aimed at fostering inclusion and institutional change to address intersecting layers of identity and experience—disability is not often spoken about as one possible dimension of intersecting exclusions. Liasidou has described how disability intersects 'with other sources of social disadvantage linked to race, gender and social class' (2013, 301). The ways in which gender intersects with disability to produce particular forms of disadvantage and exclusion helps to explain why in HE, the labour market, and in society in general, female students with disabilities are faring differently to their male counterparts. However, to date, gender initiatives, research and analysis have tended to overlook this dimension, focusing instead on the intersection of gender and race and/or gender and class (Lorenzo 2003; Office of the Deputy President 1997).

The total number of disabled people enrolled in HE in South Africa in 2011 was 65,342 out of a total of 2,1888,456 enrolled students (Magongo and Motimele 2011). In 2012, students with disabilities accounted for only 0.6 per cent of total HE enrolments despite constituting 3.5 per cent of the 20–29 year age group (Salmi and Bassett 2012). By 2015, the proportion of students with disabilities remained less than 1per cent of the total student population in the post-school education and training (PSET) sector (DHET 2015). It is in this context that we have begun to see calls for the HE sector to begin to take seriously the need to devise ways of adequately meeting the needs of students with disabilities and making disability a central concern of inclusion and justice initiatives (Ohajunwa et al. 2014). As the Soudien Report argued, one measure of a truly transformed HE sector is the extent to which it evinces respect for minorities such as students with disabilities (DoE 2008, 36). Yet, as Matshedisho (2010, 735) has pointed out, the NPHE which provides guidelines for the transformation of HE, includes 'only thirteen lines on equity and disabled students in higher education'.

Current predominantly narrow conceptualisations of diversity need to be broadened to include disability 'as an issue of diversity in our HEIs' (Ohajunwa et al. 2014, 115; see also DoE 2008). In acknowledging multiple marginalised identities, including gender, nationality, race, language of origin, social background, ethnicity, level of education achievement, and so on, it is equally important to recognise and celebrate diversity arising from disability as well (Mittler 2000). Valuing students' diverse capacities (Johnson and Fox, 2003) further needs to incorporate acknowledging that students with disabilities 'add to the diversity on campus' (Hartman 1993, 9), and, as a matter of justice, have the right to have their different educational needs met (Matshedisho 2010), their contribution to diversity appreciated, and their sense of belonging fostered (Moriña et al. 2013), thereby leading these students to feel safe, capable, and accepted (Ginsberg and Wlodkowski 2009). Achieving this would require rethinking and overhauling multiple aspects of university 'structures, systems, policies, practices and cultures' (Policy Paper 2011, 2) which continue to privilege non-disabled students at the expense of the full participation of students with disabilities (Youdell 2006).

While significant strides have been made with regard to providing access to HE for black South Africans from poor households, and, for this sector, the debate has moved on to look at questions of success, challenges of access remain acute for students with disabilities. Universities have argued that while they are not denying students with disabilities access, in many instances they are not able to accommodate these students because they do not have appropriate facilities to meet their needs. Providing expensive structural and other adjustments for the purpose of addressing access for a small minority is seen as impractical. To cite just one example: In January 2015, a wheelchair user's application was rejected by Tshwane University of Technology (TUT) on the grounds that the university was not physically accessible for wheelchair users (Monama 2015).

Both attitudinal and institutional discrimination have resulted in black students with disabilities being the most vulnerable to exclusion from the HE system (DoE 2001). Moreover, these students have even lower success and throughput rates and higher dropout rates at the end of their first year of study than their non-disabled peers (Mpofu and Wilson 2004; see also DHET 2012; DHET 2013). Given that there has not been a formal policy aimed at addressing the inclusion of students with disabilities in the South Africa's PSET system, the Strategic Policy Framework on Disability for the Post-School Education and Training System was implemented in 2018 to 'guide the improvement of access to and success' of this group within this system (DHET 2018, i). It is therefore hoped that 'through the implementation of this strategic policy framework, transformation and redress with regard to full inclusion, integration and equality for persons with disabilities in the post-school education and training system, will be accelerated' (DHET 2018, i).

However, as a number of South African studies (Eneya et al. 2020; Vergunst and Swartz 2020; Lourens and Swartz 2020; Chiwandire 2020; Dalton et al. 2019; Simui et al. 2019; Mbuvha et al. 2019; Ramaahlo et al. 2018) have shown, the enactment of policy is not a panacea. Rather, attention needs to be focused on the wide discrepancies that continue to exist between policy and practice. The enactment of inclusive education-oriented policies and the provision of funding are 'no guarantee of effective or even adequate implementation (Duggan and Byrne 2013, 55). This gap results, as the South Africa's Strategic Policy Framework on Disability for the Post-School Education and Training System shows, in students with disabilities who continue to experience discrimination in the post-school education sector and continue to encounter institutional practices that fail to consider both their learning and wider support needs (DHET 2018).

As Slee (2001, 114) notes, even in countries with well-established inclusive education policies, the expectation is often that the previously excluded are to be 'included into an unchanged system', calling into question the inclusion rhetoric of students with disabilities in HEIs (Armstrong et al. 2011). This discrepancy between policy and practice has been noted in a number of South African studies (Lyner-Cleophas 2019; Simui et al. 2019; Mutanga 2017; Chiwandire and Vincent 2017; Ohajunwa et al. 2015). As the Strategic Policy Framework on Disability for the Post-School Education and Training System notes, despite national policies aimed at the inclusion of persons with disabilities, South African HEIs still manage disability support in a fragmented way, as if it is separate from other transformation and diversity programmes and initiatives (DHET 2018). While policy calls on lecturers to adopt accessible teaching methodologies and for greater disability awareness on the part of lecturers and non-disabled students (DHET 2012), a systemic approach which includes support staff, management and lecturers in the process of disability inclusion has remained elusive (Lyner-Cleophas et al. 2014).

The obligation on the part of educators to 'reasonably accommodate' (White Paper 6 and Article 24 of UNCRPD) students with disabilities continues to be largely unmet with few lecturers adapting their teaching styles to meet the special educational and other needs of students with disabilities (Chiwandire 2019). In addition to that, research in South Africa (Matshedisho 2007; Lyner-Cleophas et al. 2014; Lyner–Cleophas 2016; Van Jaarsveldt and Ndeya-Ndereya 2015) has shown that some lecturers hold negative attitudes towards their students with disabilities, and, as Matshedisho (2010) points out, it is these attitudes which keep lecturers from appreciating and experiencing the full potential of students with disabilities to enhance diversity and the learning experience of all students.

While inclusive policies may be in place, whether or not students with disabilities are reasonably accommodated in learning environments depends ultimately on educators themselves and the extent to which they are or are not willing to make changes to make it possible for students with disabilities to learn, flourish and feel included (Ndlovu and Walton 2016). Yet, concerns have been expressed over lecturers' negative perceptions and low academic expectations of the capabilities of students with disabilities, and the reluctance on the part of many lecturers to make changes to their curricular or teaching practices to accommodate and enhance the learning of students with disabilities—despite the fact that research suggests that such changes benefit not just students with disabilities, but enrich the learning of all students (Ndlovu and Walton 2016). A persistent problem is the tendency on the part of lecturers to transfer the responsibility for catering to the diverse learning needs of students to support services on campus, such as Disability Units (Van Jaarsveldt and Ndeya-Ndereya 2015; Mutanga 2019; Mutanga and Walker 2017; Ohajunwa et al. 2015; Mayat and Amosun 2011).

Negative attitudes and stereotypes, not just on the part of lecturers, but also on the part of non-disabled students towards students with disabilities marginalise students with disabilities (Simui et al. 2019; Lourens and Swartz 2016; Phatoli et al. 2015; Kasiram and Subrayen 2013; Swart and Greyling 2011; Ramakuela and Maluleke 2011; Matshedisho 2010). In their study of students with visual impairments, Lourens and Swartz (2016) found that some participants did not feel easily accepted by their sighted peers, and this subsequently made it difficult for the latter to welcome the former into a friendship group. A mainstreaming approach that moves away from the relegation of disability to margins of campus life and one that truly begins to foster inclusivity would require conscientisation and sensitisation of all staff and students (Hlalele and Alexander 2012; see also Lyner-Cleophas et al. 2014). Without such initiatives, universities will remain discriminatory environments where students with disabilities lead restricted lives and are systematically disadvantaged due not to being disabled, but to being expected to function in environments that are disabling.

Given that black students with disabilities continue to be the most vulnerable to exclusion from the HE system in South Africa (DoE 2001), there is an urgent need for HEIs to formulate strategies to break down barriers to study (Vickerman and Blundell

2010). However, these need to be firmly rooted in the experiences of students with disabilities themselves and implemented in a coordinated and informed way, rather than being fragmented and imposed on students with disabilities. It is widely acknowledged, however, that South African HEIs are failing in this regard, with diversity, social justice and transformation initiatives targeting forms of exclusion other than disability at the cost not only of students with disabilities, but as many scholars have pointed out, also compromising meaningful transformation as such (Ntombela 2013; Ohajunwa et al. 2014; Ndlovu and Walton 2016).

In this context, the White Paper for Post-school Education and Training calls for 'research into disability in HEIs' (DHET 2013, 7). This book is one attempt to fill this lacuna. Bringing together the perspectives of contributors from many different South African universities. This book is among the few which adds to the body of knowledge on the experiences of students with disabilities in HE from the perspectives both of students with disabilities and those, such as staff members of Disability Units, who work with disability and inclusion challenges on a daily basis. In his 2000 paper, 'Constructing inclusion: lessons from critical, disability narratives', Biklen (2010) expressed his concerns over the dearth of research giving persons with disabilities themselves a voice with regards to issues affecting their daily lived experiences. Instead, he argues, 'disability so often gets interpreted through the dominant culture's non-disabled lens' (Biklen 2010, 338). Similarly, Hosking (2008, 12) has argued that, very often, 'able bodied people think about disability from their abled perspective'.

The premise of this book is that if HEIs in South Africa are to become environments conducive to the flourishing of all students, including students with disabilities, knowledge and awareness of how we are failing needs to start from the perspectives of the marginalised and excluded groups themselves, as they are the 'experts' when it comes to their own requirements in any given situation (University of Liecester 2016). This book is a contribution not only to the South African HE transformation conversation but also to a wider global conversation about inclusive education—a conversation in which voices from the Global South have been muted at best. As Peters et al. (2005, 140) have pointed out over a decade ago, literature on inclusive education 'derives largely from scholars and academics in the North, with little input from consumers, e.g. disabled people, and in some cases may be poorly suited for countries of the South'. However, the concept of inclusive education needs to be contextually interpreted—'as different meanings in different contexts' (Swart et al. 2002, 176). While there is a small but vibrant body of South African critical disability scholarship, research to date has largely been published in the form of individual papers. In this book we bring several of these voices together, giving South African researchers, academics and PhD scholars who are currently working hands-on with disability in HE research, a voice and a platform to report on their experiences in relation to students with disabilities in South African HEIs.

We take as our starting point the proposition that students with disabilities can be seen as canaries in the coal mine of South African HE inclusion debates. Their experiences point to the multiple ways in which existing norms and practices are formulated around a set of assumed normalities that need to be questioned and reconfigured. The idea of 'inclusion' is critiqued, since it implies inclusion into ways of being and doing that exclude and marginalise. In this book we offer a diverse range of perspectives in order to suggest what it might mean for universities to create cultures that are friendly to disability. These chapters provide new insights into the multiple ways in which dominant norms and practices impact on those whose lives and experiences they exclude, ignore, denigrate, and fail to recognise as fully human and deserving of equal respect and consideration.

This book offers a South African perspective which explores the intersection of multiple aspects of students' identities, but places the experiences of students with disabilities centre stage for the first time in the South African HE transformation, equity and inclusion debate. While previous literature has focused mainly on obstacles and challenges faced by students with disabilities, contributors to this book have attempted to provide solutions and share experiences of best practices. Rather than focusing on disability as a characteristic of individuals, the book takes the perspective that social environments and relationships are disabling and that it is the latter that need to change rather than locating the challenges in the disabled person who is then constructed as needing to find ways of 'fitting in' to society.

The various contributions cover a wide spectrum of concerns, from flexible and accessible curricula; to questions of funding, assistive technology, conscientisation and sensitisation of educators, availability of monitoring mechanisms to ensure effective implementation of inclusive education policies, participation of students with disabilities in sport and recreational activities, accessibility of built environments, both academic and social, health promotion, and sharing responsibility for inclusion. Sithabile Ntombela's chapter sets out to understand how students with disabilities experience academic support, and whether this support is adequate in meeting their diverse learning needs. Deploying a social constructivist approach to understanding the academic support needs of students with disabilities, Ntombela identifies various barriers that hinder the academic progress and flourishing of students with disabilities and criticises the practice of enrolling students with disabilities, but then failing to provide them with appropriate support to participate with success once they are enrolled. This chapter calls for advocacy campaigns aimed at raising awareness about disability which advocates for the right of students with disabilities to be reasonably accommodated and for their educational needs to be meaningfully supported if they are to succeed academically.

Open distance learning (ODL) is often vaunted as having a critical role to play in ensuring the right to 'education for all'. Institutions providing this mode of learning brand themselves as 'open', 'accessible', 'flexible', 'supportive' and 'affordable'. Moeketsi Letseka and Sindile Ngubane-Mokiwa's chapter critically explores ODL from the perspective of students with disabilities, raising concerns about the exclusion of students with disabilities from policy decisions that affect their lives. These challenges notwithstanding, the authors acknowledge the important role played by support initiatives such as the University of South Africa's Advocacy and Resource Centre for Students with Disabilities (ARCSWiD), particularly through providing academic support interventions in consultation with the academic departments with a view to enabling the University of South Africa's students with disabilities to succeed in their studies.

Historically, challenges faced by students with disabilities in accessing HEIs were attributed to limited public funding. The introduction of progressive funding models, such as disability scholarships, has served to broaden access to, and participation in, higher education for students with disabilities. These successes notwithstanding, little attention has been paid to potential flaws in the underlying values informing how public disability funding is allocated to students with disabilities. Disability funding tends to be seen uncritically as a 'good in itself'. Desire Chiwandire and Louise Vincent examined funding mechanisms of selected countries, including the United Kingdom, the United States, Canada, Australia, South Africa, and India, to ascertain their contribution to enhancing access, equal participation, retention, success and equality of outcome for students with disabilities who are funding recipients. This chapter highlights barriers such as the bureaucratisation of funding application processes, cuts in disability funding, means-test requirements, minimal scholarships for supporting part-time and distance learning for students with disabilities, and inadequate financial support to meet the day-to-day costs that arise as a result of disability—all of which place students with disabilities at a substantial educational disadvantage compared to their non-disabled peers.

Deirdre van Jaarsveldt and colleagues explored the question of direct engagement between the disabled and non-disabled sectors of university communities. This chapter argues that students with disabilities sharing their experiences is a critical component of promoting inclusivity. However, direct engagement does not always have the desired outcome, and is sometimes met with opposition. Self-advocacy, then, needs to work in concern with advocacy partnerships with, and support of, the non-disabled members of the university community. This chapter recommends that future engagement opportunities and research should extend to staff with disabilities, and that it might also be a worthwhile effort to focus on the affective aspects of transformative dialogue, such as empathy development and the effects of vulnerability.

Richard Vergunst's very personal chapter draws on his own experience as someone living with an invisible disability which is obsessive-compulsive disorder (OCD) and he discusses how disability affects academic inclusion and how he and his co-participant have dealt with these challenges. Vergunst's hope is that by voicing his personal story it can become a catalyst for raising further awareness and promote an open discussion of a very pertinent but underrepresented issue in HE. This chapter challenges us to look beyond a narrow institutional approach to social inclusion and to focus on the individual as well, so that the measure of inclusion is the student's opportunity to enjoy positive, supportive relationships with peers and educators at university.

Literature on the inclusion of students with disabilities often focuses on academic inclusion with little attention paid to social inclusion—in sport, recreation and extracurricular activities, for example. Jacqueline Moodley and Tinovimba Patsika's chapter on students with disabilities' participation in athletics enters this gap. This chapter looks at how students with physical disabilities navigate university to successfully balance their studies and sporting careers. Drawing on in-depth interviews with students at one university, the chapter looks at factors which both facilitate and hinder participation of students with disabilities in sport at university. The authors call on HEIs to regard the issue of participation of students with disabilities in sport and recreation seriously, and to provide enabling environments to foster equal participation in extracurricular activities for this group as a central component of the overall HE experience.

Sibonukuhle Ndlovu reports on interviews with students with disabilities studying three different professional degrees—medicine, law, and education (selected because their associated skills are considered as scarce in the country) at one South African university. This chapter describes these students' experiences of the obstacles they encountered across the three professional programmes which made it difficult for them to complete their respective programmes within the stipulated minimum time-frame. These include, for example, teaching practices, learning media and field-practice, inaccessible physical environments, lack of public transport, negative attitudes, and funding that is not adequate to support their learning.

Tshifhiwa Ignetia Mashau calls out South African universities for not taking the health promotion of students with disabilities in their inclusive education initiatives seriously. Mashau outlines the importance of health promotion for inclusive education and argues that it is important to understand students with disabilities' experiences if universities are to devise appropriate ways to support and promote the health of students with disabilities. Barriers to an inclusive approach to health promotion non-compliance with institutional policies aimed at advancing the rights of persons with disabilities; lack of will on the part of management to ensure compliance; lack of finances to fund health promotion initiatives and lack of collaboration and coordination in the provision of services. This chapter calls for rigorous training and advocacy which would incorporate management, administrators, and academic staff.

Oliver Mutanga uses cognitive interviews to explore the academic experiences of students with diverse disabilities at two South African universities. In this chapter, Mutanga describes four themes that emerged from his research: language, socio-cultural constructions of disability, identity, and the question of transitions into higher education. This chapter also highlights suggestions from participants concerning how to address concerns related to undertaking disability research.

Emerging from their work with Disability Unit Staff Members (DUSMs) based at ten different universities in four of South Africa's nine provinces, Desire Chiwandire and Louise Vincent argue that despite calls for collaborative initiatives amongst stakeholders involved in achieving inclusive education for students with disabilities in HEIs, to date, there is still a dearth of literature focusing on the issue of responsibility. Their chapter discusses the idea of 'responsibility sharing' as seen from the perspectives of DUSMs. This chapter arises from interviews with 28 DUSMs at ten different South African universities to gain insight into whether and how shared responsibility is achieved in practice-—who is responsible for what, and what the consequences are for students with disabilities when relevant parties fail to meet their responsibilities. Here 'relevant parties' refer to DUSMs, lecturers, HEIs leadership and management, and students with disabilities—all of whom have (varying) responsibilities when it comes to achieving inclusive education. This chapter argues that the goals of inclusive education are achievable if the 'relevant parties' are willing to 'move out of their comfort zones' by not only focusing on their traditional or conventional responsibilities.

Drawing together insights from all the contributors, the final chapter of the book lays out recommendations for how we might go about making the circle bigger and coming closer to the goal of achieving inclusive education in South Africa. In doing so, this chapter discusses issues related to disability inclusion policy, practice and research mainly in the South African context.

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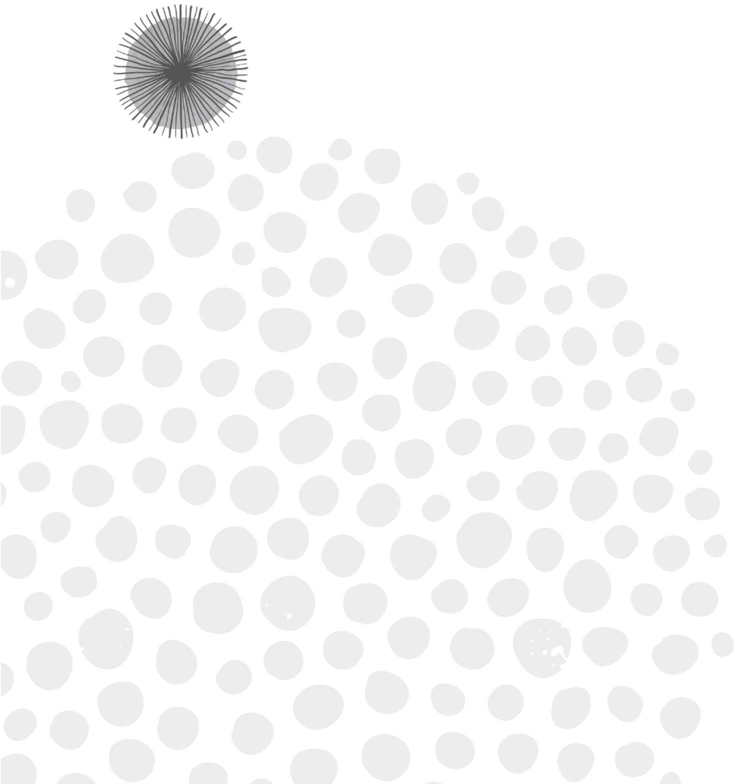
# PART 1

## HIGHER EDUCATION INSTITUTION'S LANDSCAPES



# Chapter 2

## LEARNING SUPPORT FOR STUDENTS WITH DISABILITIES AT A SOUTH AFRICAN UNIVERSITY

Sithabile Ntombela

### Abstract

Although the transition to democracy saw many South African universities increasing the enrolment numbers of historically disadvantaged students, especially black students, these institutions paid little attention to supporting these students to succeed academically, which resulted in many of them dropping out. In this chapter, Sithabile Ntombela explores the issue of access without success in relation to the inclusion of students with disabilities in South African higher education institutions (HEIs). The author draws on the findings of a qualitative explanatory study which investigated the experiences of students with disabilities at one South African university in order to explore whether or not the academic support they received from this institution was adequate to meet their daily learning needs. The participants reported various challenges impacting on their learning, including lecturers' insensitivity and lack of knowledge of how best to support the learning needs of students with diverse disabilities, inadequate permanent Disability Unit Staff Members to support the academic needs of students with disabilities, and lack of awareness-raising workshops targeting the non-disabled community—especially lecturers. The chapter calls for universities to do more to enhance the positive learning experiences of students with disabilities. Establishing awareness-raising workshops aimed at sensitising lecturers, as well as investing in professional development courses aimed at improving lecturers' skills to adopt inclusive teaching and learning practices which are inclusive of the diverse learning needs of students with disabilities, are among the recommendations made in the chapter.

## Introduction

Historically, the majority of the South African population was not able to access higher education (HE). This changed in 1994 when South Africa became a democracy and policies were revised in line with the country's Constitution, which promises all citizens the right to education, including higher education (Republic of South Africa 1996).

In 1997, the Department of Education (DoE) published Education White Paper 3: A Programme for the Transformation of Higher Education (EWP 3), a policy that sought to restructure higher education into a single coordinated system (DoE 1997). In line with the Constitution (RSA 1996), one of the objectives of EWP 3 is increasing access to, and participation of, women, black people and people with disabilities in HE. The National Plan for Higher Education (DoE 2001, 40) tables the South African government's commitment to, and expectation of, higher education institutions (HEIs) increasing the admission of students with disabilities.

Four years later, the Education White Paper 6: Special Needs Education—Building an Inclusive Education and Training System (EWP 6) came out, purposed to drive the creation of an inclusive system of education that celebrates and responds to diversity amongst learners (DoE 2001a). According to UNESCO (2003, 4), inclusive education is concerned with addressing 'the learning needs of all children, youth and adults with a specific focus on those who are vulnerable to marginalisation and exclusion'. Addressing the learning needs of this group requires 'responsive educational opportunities' (UNESCO 2003, 4). Howell (2006, 164) acknowledges the historically disadvantaged position of students with disabilities: a position that makes them 'an important target group to reach in broadening the social base of the higher education system'. Ten years later, the numbers have increased, but not significantly, as the Department of Social Development estimates that one in five people with disabilities are enrolled in higher education (RSA 2016).

This chapter reflects on the findings of a single case study that investigated the lived experiences of students with disabilities at a South African university. This was an exploratory study conducted between February and April 2016 to establish how students with disabilities experienced academic support at this institution. It is hoped that the findings would highlight what the follow-up study could focus on, as well as point to areas that require attention in teaching and learning within the institution to ensure that students with disabilities receive the necessary support to succeed in their studies. The study was significant in that it acknowledges and privileges the experiences of students with disabilities in an attempt to understand how disability and disablement can intersect in education.

As South African universities are transforming and admitting more students with disabilities into their programmes (Nzimande 2010; Ntombela and Mahlangu 2019), it is critical that their admission is not just a numbers game, but that it is qualitatively meaningful, allowing their voices to be heard, and ensuring that their learning needs are identified and properly addressed. This is important as students with disabilities are not a homogenous group. Apart from their different disabilities, they also face various challenges academically and socially. Therefore, it is important to understand their experiences as students in HE as this provides a window into whether institutional cultures are disabling or not, whilst also giving valuable feedback in terms of what support is available, where the gaps are, and what can be improved to ensure that these and future students benefit optimally from teaching and learning activities.

## Transformation of higher education: issues and challenges of making the circle bigger

South African HEIs have engaged with equity goals as captured in the HE policy framework and proclamations of the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006), albeit influenced by their own contexts and prevailing patterns of inequalities. They have heeded the call and made the circle bigger through increased access and enrolment of students who were previously marginalised (Ntombela and Mahlangu 2019), including women, black people, and people with disabilities. Whilst increasing higher education access for these students is good and necessary as it is a move away from anti-discriminatory legislation, practices, and policies of the past, and because it increases their chances of being economically active, we should always remember that this ‘has more than numerical consequences’ (Aluko 2011, 122). In other words, increasing access has to be linked to increased support and throughput (Ntombela and Mahlangu 2019); otherwise, the whole exercise becomes a revolving door.

Similarly, the National Plan for Higher Education highlights the interrelatedness of access and outcomes, emphasising the need for HEIs to ‘ensure that they have effective programmes in place to meet the teaching and learning needs of the students they admit’ (DoE 2001, 25). This is reiterated by Mutanga and Walker (2017), who emphasise the provision of opportunities for access and success in HE. Therefore, redressing inequalities, if done properly, is both a quantitative and qualitative exercise in that whilst the numbers of previously marginalised students increase, the quality of teaching and learning also has to improve through adequate support, resource provision, and ongoing, relevant staff development.

This sentiment was also emphasised by the Minister of Higher Education Blade Nzimande (2010), when addressing the Higher Education Disability Services Association at the University of the Free State. He expressed concern that:

> Disability should not be an added disadvantage to students already disadvantaged by a lack of funding and other barriers to success in higher education. It is important that we ensure students with disabilities are not made more vulnerable by our practices and policies and this means identifying clear and specific strategies for support to these students.

Minister Nzimande went on to highlight the need to transform the curriculum and for universities to create systems that would:

> Support the teaching and learning of disabled students, and this includes examining the design, format and methods of teaching built into university curricula to respond to the special needs that students with disabilities have.

Nzimande’s concerns emanated from two important and complementary documents: EWP 3 and EWP 6. Both these White Papers seek to redress the inequalities of the past by increasing access to, and participation of, those groups that were historically marginalised (DoE 1997; DoE 2001a). Although South African HEIs have opened their doors to students with disabilities, not much research has been done to understand how these students are experiencing university life. This chapter reports on an exploratory study that explored the experiences of these students in regard to the availability of academic support at their institution.

Many students with disabilities enrolled in HE programmes lack self-advocacy skills (Kraglung-Gauthier et al. 2014). The effect, unfortunately, is worse when lecturers are not aware of these students' need for reasonable accommodations to enable them to succeed. For example, emailing class notes or slides in advance would enable blind students and those with limited vision to convert them to their preferred print format, thus giving them a chance to take part in the class discussions, but this rarely happens, if at all. It came as no surprise, then, when the Minister expressed concern that many students with disabilities drop out of university whilst many more fail to complete their degrees in the minimum time (three or four years).

> While we must all appreciate the work already done, there are still significant challenges to be overcome in our system. These reflect a combination of factors, but include a lack of coherence in the higher education sector as to what comprehensive disability support in universities entails (Nzimande 2010).

According to EWP 3, the South African HE system has to transform in such a way that it responds to the new order, new realities and even new opportunities. To make this a reality, the Department of Education has proposed an increase of access and participation of those previously marginalised—a list that includes staff and students with disabilities (DoE 1997). In practice, this means creating teaching and learning environments that are enabling by reviewing curricula, modes of delivery, and models of teaching and learning to ensure that they are responsive to the needs of admitted students that can create opportunities for success.

Lyner-Cleophas et al. (2014) argue that in HE, disability support is managed in a disjointed manner, divorced from the current transformation programmes in spite of the DHET's recommendation to adopt a system-wide agenda to implement inclusion. This suggestion to adopt 'a systemic approach to inclusion' (Lyner-Cleophas et al. 2014, 1) is the way forward, as this would enable all stakeholders to participate in transformation and diversity programmes, thus gaining insights into the goal and its significance.

Due to their impairments, students with disabilities need additional support to succeed in learning. Tugli et al. (2013) argue that lack of access and support can lead to these students facing social and academic exclusion. Howell (2006) observes that two key barriers to meaningful participation of students with disabilities in HE are teaching and learning that is non-inclusive, and inadequately conceptualised and/or resourced learning support services. This situation is worsened by the fact that:

> Most support services…tend to operate separately from, or have limited collaboration with, broader teaching and learning support initiatives within the institution. Where some link exists, the collaboration is mostly with student

> counselling services, rather than with those dealing directly with teaching and learning such as academic development programmes (Howell 2006, 168).

Theorising teaching and learning support in HE, Howell (2006) cites Simpson (1996), who posits that there is a critical distinction between learner services and learning development. The former pertains to career guidance, reasonable accommodations, counselling, and healthcare which is accessed outside of academic services, whilst the latter refers to assessment support, tutorial support, and/or professional development that is offered at the programme level (Howell 2006). Aluko (2011) also differentiates between learner invitation and learner hosting. Learner invitation is concerned with matters pertaining to access, admissions, and placement, whereas learner hosting is about academic provision, service, and increasing capacity (Aluko 2011). Both services are necessary, but it is important that they are made available at appropriate levels and that no attempts are made to replace one with the other.

## Staff development as part of transformation for inclusion

Kraglund-Gauthier et al. (2014) argue that effective inclusion requires synchronisation of a number of components, namely professional development, administrative support, family involvement, accommodation and supports, training and relationship building, as well as vision and attitude (Kraglund-Gauthier et al. 2014, 6). This suggests the importance of staff development to ensure that inclusive learning environments are created where there are adjustments for students with disabilities to have positive academic outcomes (Hewett et al. 2017).

There is evidence that the commitment of teaching staff to innovations (like inclusion) is largely dependent on the training they have received, and that their competence to meet diverse needs is influenced by acquired knowledge and skills that support them identify and adapt the curriculum and teaching methods in accordance with individual student needs (Kraglund-Gauthier et al. 2014). When Lyner-Cleophas et al. (2014) report that university staff (across HEIs in South Africa) lack awareness about disability policies and practices, it explains why the implementation of inclusion has been slow despite well-developed legislative and policy frameworks. This again reinforces the importance of a systemic approach to innovations.

Matshedisho (2007) conducted a comparative study between South Africa and the United Kingdom to understand how students with disabilities are supported. His findings show that close to half the people working in HE in South Africa ‘are not familiar with government policies that provide guidelines for the disability framework’ (Matshedisho 2007, 689), yet they are expected to provide quality service to all students. Tinklin et al. (2004), cited in Tugli et al. (2013, 357), argue that students with disabilities are a challenge to HEIs in relation to much broader issues, including ‘negative attitudes, lack of appropriate services, social integration, curricular barriers and progression’. This suggests that admitting students with disabilities into HE programmes when academic and support staff have no understanding of how to provide reasonable accommodations to enhance the teaching and learning process can be a serious barrier to these students’ participation. Whilst the critical role of professional development in the creation of inclusive learning environments in HE is acknowledged, the case study reported here did not explore the competencies of academic and support staff working with students with disabilities, because the objective of the study was limited to students' experiences of academic support at this university.

## Discourses of difference and their impact on higher education

Medical discourses have influenced educational provision across the world, including South Africa. The most dominant has been the medical, or deficit, discourse (Fulcher 1999) which portrays disability as physical incapacity, or, as Oliver (1990) maintains, an individual problem. This discourse is mainly preoccupied with what is wrong with individuals and completely disregards factors within educational institutions that prevent learners from participating meaningfully (Fulcher 1999).

The negativity created by the perpetuation of deficit stereotypes of disability (Oliver, 1990) could be what causes many students with disabilities to be reluctant to be identified as having a disability to such an extent that they tend not to 'tell students or lecturers about their impairment' (Tinklin et al. 2004, 3). Kraglund-Gauthier et al. (2014) make a similar claim that students with disabilities are sometimes reluctant to use assistive devices in an attempt to disguise their difference. This was found to be the experience of the four participants in this case study. There could be many reasons for their reluctance, but, clearly, there is fear that once their disability status is known, they will not be treated as other students, but rather pushed to the margins both academically and socially.

As more societies consider disability as a socio-political matter (Barnes 2007), the enrolment of students with disabilities has increased in HEIs. In South Africa, the White Paper on Higher Education Transformation (DoE 1997) urges HEIs to redress past inequalities by increasing access and opportunities for success, especially for historically marginalised students. Similarly, Inclusive Education (DoE 2001a) promotes the development of an inclusive education system as a building block of a humane society. Therefore, the development of inclusive learning environments is the responsibility of all institutions, irrespective of level. However, as Fullan (1996) cautions, it is important that this process of transforming institutions is driven and guided by a shared vision and leadership if the desired change is to take place.

## Purpose of the study and research methodology

The study objectives were to understand how students with disabilities experience academic support at this university, and whether this support was adequate for their learning needs. As such, a qualitative case study design located within an interpretive research paradigm was used. Robson (2002) defines an interpretive researcher as someone who seeks to describe and interpret the phenomenon under study in an attempt to derive a shared meaning. To understand the lived experiences of these students at this university, two critical research questions were posed:

(a) How do students with disabilities experience academic support at this university?
(b) How adequate is this support for their learning needs?

## Theoretical framework

This study was located within the broad framework of social constructivism, which views knowledge as socially constructed and negotiated as participants seek to improve their 'understandings of their worlds' (Donald et al. 2002, 100). The thrust of this framework is how meaning and understanding grow out of social interactions or human practices (Crotty 1998). Ntombela (2017) argues that it is particularly important for students with disabilities to take part in the retelling and rewriting of new narratives and scripts about their experiences.

## Data generation and sampling procedures

Individual semi-structured interviews were used to discover how each of the participating students was experiencing academic life at this university. A list of ten Bachelor of Education students with disabilities who had disclosed their disability status was obtained from the Disability Office. These students were emailed invitations to participate in the study. None of the students responded, and after two weeks of resending the invitation, the students were contacted by telephone. Only four (4) students from the list (three males and one female) agreed to an interview.

The profiles of participating students are presented below, and they have been given pseudonyms:

Table 1: Sample Profile

| Pseudonym | Sex | Year of study | Disability |
|---|---|---|---|
| Msizi | Male | 4th | Visual impairment |
| Sam | Male | 2nd | Mental health condition |
| Sbuda | Male | 2nd | Hearing impairment |
| Phila | Female | 4th | Physical disability |

The case study university was selected because of convenience. At the time of the conceptualisation of the study and data generation, the author worked as a champion for Student Support at the campus where the study was conducted. Each of the four students was invited to attend an interview at a time that was convenient for them. The interviews were held in the author's office, and, with each student's permission, the interviews were recorded. Each interview lasted for about 45 minutes. Since the author worked in Student Support on this campus, the students seemed to trust her as part of their support structure, and none of the students appeared timid to share their experiences. Despite this familiarity with students, the author respected their right to privacy and remained mindful that each student is unique and likely to have different interpretations of their experiences. To ensure the findings were not influenced or affected by the author's familiarity with the context, the students' claims were later corroborated with the resident Disability Officer who confirmed that such experiences were typical of students with disabilities' experiences at that campus. This was done without compromising the identity of the participants.

Data generated from the interviews were analysed by what Robson (2002: 476) refers to as data reduction, data display, and conclusion drawing. Summaries were made after each interview in an attempt to make meaning of participating students' experiences of academic support. These summaries were later shared with the four participants (member checking) (Robson 2002). The two research questions were used as key themes to frame the data.

A major limitation of the study was the size of the sample. Although ten students were invited to participate, only four availed themselves. This reluctance to participate led to the study relying on a very small sample of participants. However, since this was an exploratory case study, there was no intention to generalise from the findings, but the findings pointed to the need to conduct a larger study that would assist the institution to understand the depth of the problem. As such, the findings were useful in providing ideas that could be pursued in further studies (transferability).

All ethical requirements were considered and addressed, and a certificate of compliance (HSS/0948/012) was obtained from the university in question. Participation was voluntary, and identified students were informed of this and their right to withdraw without fear of marginalisation. All the names used to identify students are fictitious.

## Findings and discussion

This was an exploratory case study with the objective to understand how students with disabilities experience academic support, and to establish how adequate students feel this support is in enhancing their learning.

### How students with disabilities experience academic support at this university

Since disability is both a personal and social matter, the four students provided data that were useful in painting a picture of how they experience academic support on this campus.

> The Disability Unit mainly raises awareness, but there is no attempt to educate the teaching staff about disabilities and the needs that students have. For example, when you tell some lecturers that 'I need ten extra minutes per hour to complete the test as per my disability' the usual response is 'No, you are all the same to me, I cannot give you more time than other students; that would be unfair.' Some lecturers also are not sensitive. I once alerted a lecturer that I could not see what was on the board and he shouted for the whole class to hear 'How can you not

> see when you are seated right in front?' He made me a laughing stock instead of investigating what the source of my problem is (Msizi).

This student was concerned that lecturers (teaching staff) are not knowledgeable about disabilities, and some lack the sensitivity in handling issues affecting students with disabilities. This confirmed Matshedisho's (2007) claim that some people working in HE are not familiar with government policies that provide guidelines for disability frameworks. Msizi's unpleasant in-class experience confirmed this insensitivity and lack of knowledge. The cited experience was very unfortunate and likely to make other students refrain from asking for support from that lecturer. Orr and Bachman Hammig (2009), cited in Kraglund-gauthier et al. (2014), claim that students are more likely to seek assistance only from those lecturers they perceive as supportive.

This experience highlights the importance of being sincere and willing to listen when we encourage students to speak out and to draw attention to practices that exclude them. We cannot ask them to come forward and then ridicule or victimise them. This points to the need for all staff to undergo professional development where they are sensitised to these matters in order to promote the development of teaching and learning spaces that are truly inclusive.

Although Msizi has not had positive experiences with some of his lecturers, Sam seemed to have been more fortunate. We want all students to have such positive experiences where lecturers are knowledgeable and sensitive to issues of diversity:

> The Disability Officer gave me a script for my lecturers. When I have a test or an assignment, I always present this slip, which says I am entitled to extra time. This helps me a lot, as I tend to be slower than other students in completing tasks (Sam).

The only reason I could think of to explain why the two lecturers differed was awareness. One was aware and sensitive to disability/diversity issues, and the other one was not. Since the focus of the study was on students and their experiences of academic support, one is thus left speculating as to why there were differences in lecturers' responses. There are many possible answers, and it would not be fruitful to speculate. What is clear though is that people working in the same institution can have divergent views/knowledge about the needs of their students. The Disability Officer was aware and claimed she advised students how they should respond if they get similar responses.

> When I arrived, I had no idea about the Disability Unit. My hearing aid was dead (had had it since primary school) so I struggled in semester one. Sometimes classes were full and I could only stand at the door and it was impossible to lip read. Then someone told me about the Disability Unit. I then spoke to the Disability Officer and she referred me to the clinic where I had received the first hearing aid. They gave me a new hearing aid and it is working well (Sbuda).

Many students, due to numerous reasons, miss the orientation programme in the first week of the semester, and this has serious consequences for them. A lot of information is shared with first years, including information that gives them the 'heads up' about the institution and what resources are available, and where these are located. Sbuda was fortunate that he got to know about the Disability Office before failing and becoming at risk of exclusion. What this illustrates is the need to highlight the support available to students with disabilities online, as well as in the welcome pack so that students do not suffer in silence:

> The Disability Officer at … (another campus), where I did my first year, introduced me to all the lecturers for my classes and explained to them what support I needed to learn. This was very useful as it meant my condition was known even before classes started. I also got support during the exam; someone was made available to help me with underlining or turning the paper. This did not happen when I moved to this campus so my lecturers are not aware (Phila)

Phila had experienced two different treatments at the two different campuses. This was the case of the bigger the campus, the more students it has, and the more resources they have. The campus where Phila attended at the time of writing this chapter was smaller, with fewer resources than the one where she started at. This could explain why there are differences in how the Disability Unit works in comparison to the one on the case study campus.

Generally, the findings reveal that the students did not receive academic support, although the presence of a Disability Unit contributes to the positive experiences that students have. However, this does not necessarily improve lecture hall dynamics. Similar to the findings in a study by Tinklin et al. (2004), which also illustrates that there is a disconnect between policy and practice, as students report that they are still experiencing barriers that limit their participation. It was further necessary to establish if the support available was adequate for the purposes of supporting students with disabilities in their learning.

## The adequacy of available academic support

> For me it has been okay because I am partially sighted and do not require a lot of support. All I need is large print, which the Disability Office is able to provide after I submit the class notes. One student I know could not finish his teaching degree. He dropped out because of Teaching Practice in the first year. During blackboard work, this student told the lecturer that he could not write on the board because he is blind. The lecturer insisted that he must learn to write on the board if he is to become a teacher. As if to add salt to injury, she told him that she had never seen a blind teacher. The student decided to leave even though he was doing so well in other subjects (Msizi).

Some students with visual impairments should be easy to support if all they require is large print. However, the fact that the large print notes are obtained from the Disability Office confirms that these students do not receive academic support from their lecturers. Ideally, large print notes can be supplied by the lecturer instead of the student having to submit these ‘unreadable’ notes for conversion into appropriate font size at the Disability Office. This would save time and resources. This is a typical case of a lecturer who lacks awareness about disability policies and practices as highlighted by Lyner-Cleophas et al. (2014).

The case of a blind student expected to write on the board is a classic example of how uninformed some lecturers can be. The fact that the lecturer had not met a blind teacher does not mean that there are no blind teachers. This seems like a missed opportunity to seek guidance on how to work with a blind student. Sometimes this is not deliberate, but could be a result of prejudice, fear, or lack of knowledge and skills. Professional development of academic staff would raise awareness and sensitivity to such matters and prepare lecturers to make adaptations to the curriculum to meet the individual needs of students with disabilities. Unfortunately, when lecturers are ill-prepared to teach in a manner that addresses diverse learning needs, those most likely to suffer are the already vulnerable students, such as the disabled.

> Ever since I moved to this campus, I have not received support. The Disability Office is also short staffed (there are few student temps and they do not stay for long). Maybe that contributes to the problems I have highlighted, but at the other campus I was assisted in many ways. Even when going to hospital for my prosthetics I was given a student temp to accompany me (Phila).

Although the focus was on academic support, Phila felt that things could work better if the Disability Office had adequate human resources. This suggests that some students depend more on the Disability Office than on their lecturers for academic support. At the time of the study, there was only one full time Disability Officer attached to this office and a few temporary student workers on short contracts. This could perhaps compromise the work that this office does, as it means there are times when the Disability Office is unable to attend to students' issues. Since the temporary workers are students as well, one wonders if they are adequately trained to work with sensitive information.

> Last year I stayed off-campus and the buses are noisy and students make a lot of noise. By the time I got to campus, half my hearing would be gone. I am currently at risk academically because my grades were bad. By the time I went to class, I was often deaf because of the noise so I asked the Residence Office to change me to a residence on campus, but nothing happened. I had to come out because I needed help, my grades were so bad. It was not funny at all. They only changed me when the request was made by the Disability Office, which was after I got the medical report. I am now on campus and things are better. I also have a letter that grants me extra time during exams and tests, which helps. At the same time, my lecturers do not know that I have a disability. I am scared to tell. It is not easy. I am concerned that people will make a mockery of my condition, so I am afraid (Sbuda).

The testimony presented by these students suggests that lecturers are not aware of the challenges their students face due to the presence of disabling conditions. Fortunately, the Disability Office does provide some support, even though some students feel let down. The fact that there is a dedicated Disability Unit looking after their interests is something they are grateful for. The students shared some ideas about how this situation could be improved:

> Generally, the support is there, but not sufficient, because the Disability Unit needs to have more staff. The Disability Office [sic] is the only permanent member of staff and the rest are student temps who change often. During orientation or at the beginning of the year this office can inform teaching staff about what disabilities do students have each year, and how those students can be supported. Much more awareness-raising is also needed to address the stigma. Awareness workshops are organised, but these are not compulsory. Students without disabilities do not attend, neither do staff. I do not think they even get invited. Raising awareness among staff is also important so that those who teach us can understand our needs (Msizi).

The issue of raising awareness amongst those working directly with students cannot be over emphasised. Non-disabled students also need to be educated about diversity as part of their studies. As Msizi rightly said, this exercise can contribute to reducing stigma about disabilities:

> It is difficult for me to participate fully in classes where there are no microphones. Lecture halls should all have microphones to ensure sound carries well as that assists students like me to hear well. Another thing that would help is if a few seats can be reserved in front to enable those with sight and hearing problems to sit close to the lecturer or the projection screen. Sometimes hearing aids fail, batteries go flat or something, so reserving some seats can help (Sbuda).

It was interesting to hear the suggestion of seat reservation for students with disabilities, because three of the four participating students were not keen to disclose their disability status. It was not clear how these seats would be accessed without fellow students figuring out that they had some disability. What this indicates is what Tugli et al. (2013) highlighted when they argue that the presence of different disability categories poses a serious demand on university resources, as each disability may require that different adaptations be effected in the learning environment. However, the university can use the Teaching Development Grant to upgrade teaching venues in such a way that students with and without disabilities benefit.

## What does this tell us about the experiences of these students?

From the students' experiences, there seems to be differences in how staff members react to scripts for extra time. My assumption is that not all staff members are aware that students with disabilities may require different reasonable accommodations to enable them to perform optimally. The fact that not all disabilities are visible could add to the problem, as lecturers might think a student is taking chances when they ask for an accommodation.

None of the participating students had disclosed their disability status to either staff or other students, except to very close friends, although they wanted teaching staff to make accommodations for them. This reluctance to come out is understandable, especially if one considers Msizi's experience, and that of the blind student who reportedly dropped out. This emphasises the need for universities to plan professional development programmes that equip teaching personnel with skills, values, and attitudes that embrace diversity in their classes. It also highlights the need to educate staff about policies that guide provision. It is important, therefore, that strategies are found that disseminate policies and that raise awareness about practices that continue to alienate some students. This could also be used to disseminate best inclusive practices from local and international contexts.

The institution in this case study took great strides to provide meaningful support for students with disabilities through the Disability Unit. However, the findings indicate that much work still needs to be done to ensure that all students with disabilities have positive learning experiences at this institution.

One of the key findings is the urgent need for the professional development of teaching staff (faculty) to ensure that the curricula is fully accessible to all students and that reasonable accommodations are available to those in need. There is a need to develop support staff as well, as they also work with students at various stages during the course of their studies. As indicated earlier, Howell (2006) highlights two key barriers to meaningful participation of students with disabilities in higher education, namely, teaching and learning that are non-inclusive, as well as ill-conceived and under-resourced learning support services.

The findings also point to the need to support all staff in developing competencies required to create inclusive teaching and learning environments, and those in leadership can achieve this through continuous staff development programmes and careful monitoring of the institutional culture. There are governmental and university policies that promote access, equity, and social justice, and it is in the interest of this university to ensure that all policies are cascaded to all staff so that the overall culture changes to a more inclusive one. If staff members are not familiar with university policies, the likelihood is that they can violate students' human rights without even realising it. It is also the expected role of universities to take the lead as knowledge producers and trendsetters in the creation of a just and humane learning community.

Properly conceived staff development will address issues of ignorance in the form of some staff refusing to make time adjustments for deserving students and assist staff to explore various ways to support students with disabilities. It is also important to standardise services across the university so that students receive the same support irrespective of where they are located within the institution. Most importantly, communication between the Disability Units and the faculties needs to be promoted to ensure that students' support needs are communicated to those who teach the students. This will create a platform for dialogue about how the institution can break the cycle of disadvantage and marginalisation created by the intersection of disability and disablement in education.

## Conclusion

The experiences of participants in this study point to the need to facilitate advocacy campaigns to raise awareness about disability as a human rights issue, and to advocate for the right of students with disabilities to reasonable accommodations. This demands that the HEIs be developed into learning environments that are inclusive. Developing inclusive learning environments is not a once-off event, but a journey that never ends (Mittler 2000) as each day brings new challenges which need to be dealt with. When institutions decide to admit students with disabilities, it is important to remember that they are students first. Once accepted into university programmes, there is an obligation to provide them with positive educational experiences, because their success is just as important as that of other students. At the end of the day, all students matter.

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# CHAPTER 3

## DISTANCE LEARNING OPPORTUNITIES FOR STUDENTS WITH DISABILITIES

Moeketsi Letseka and Sindile Ngubane

### Abstract

Given its potential to support students from various distant geographical areas, flexible learning processes, as well as its emphasis on student-centeredness, Open Distance Learning (ODL) has become a popular mode of learning in African universities, including South African universities. However, much of what we know about the impact of ODL on widening educational opportunities in South Africa has mainly focused on non-disabled students. This dearth of literature focusing on the inclusion of students with disabilities in ODL is raised as a matter of concern in this chapter. It particularly explores the learning opportunities for students with disabilities enrolled at the University of South Africa (Unisa), a major player in the delivery of the ODL mode of learning. Although Unisa brands itself as an ODL institution which promotes inclusive values of *openness*, *accessibility*, *flexibility*, *affordability*, and *supportiveness*, greater efforts aimed at the inclusion of students with disabilities are needed. The barriers that students with disabilities face, the chapter argues, can be attributed to the institution having adopted a one-size-fits-all approach that treats students with disabilities as a homogeneous group. The chapter highlights, for example, that black students with disabilities are disadvantaged by their race, disability, class, and gender in comparison to their non-disabled peers as well as in comparison to white students with disabilities. The chapter commends Unisa's Advocacy and Resource Centre for Students with Disabilities (ARCSWiD) for initiatives ranging from providing assistive devices to campus-wide advocacy and disability awareness-raising initiatives. The chapter notes, however, that fully embracing inclusivity for students with disabilities needs to include encouraging lecturers to employ accessible

curriculum design, teaching and assessment practices which also address the learning needs of students with disabilities if this group is to succeed in higher education.

## Introduction

In this chapter we flesh out learning opportunities for students with disabilities in the open distance learning (ODL) context. In the South African context, questions related to advancing equal learning opportunities for students with disabilities in higher education in general, and in ODL in particular, are often associated with achieving the notion of inclusion. However, as Mutanga (2015) points out, notwithstanding international treaties, national legislation and institutional policies, there are no specific directions on how South African higher education institutions ought to address the needs of students with disabilities. The reason for this, Mutanga observes, is that 'the concept of inclusion is not straightforward' (2015, 25). He is therefore concerned that 'disability issues have been trivialised in redressing inequalities, particularly in higher education', (2015, 2) and attributes this to the fact that students with disabilities make up 'less than 1per cent of the total student population' in higher education, hence students with disabilities struggle 'to enjoy fairness and justice in the way in which they are treated at universities' (Mutanga 2017, 30). Little is known about the specific experiences of students with disabilities in South African higher education as the field is under-researched, with only a small number of studies to provide much-needed data (Mutanga and Walker 2015). This point is confirmed by South Africa's Office of the Deputy President's (1997) Integrated National Disability Strategy, which states that 'there is a serious lack of reliable information on the nature and prevalence of disability in South Africa. This is because…disability issues were viewed chiefly within a health and welfare framework. This led naturally to a failure to integrate disability into mainstream government statistical processes'. While the White Paper on the Rights of Persons with Disabilities (2016, 4) of the Department of Social Development (DSD) does not attempt to define disability, it recognises that disability is an evolving concept. The DSD's position is that 'disability is imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments'(2016, 4).

The White Paper for Post-School Education and Training of the Department of Higher Education and Training (DHET) notes that 'despite … strong legislative and policy framework[s] for addressing disability in the education sector, access and support for people with disabilities remain limited' (2013, 45). This is not helped by the fact that 'there is less funding for and resourcing of disability units at historically black institutions compared to historically white institutions' (DHET 2013, 46). The DHET further notes that 'this situation has been exacerbated by the fact that disability grants are not provided directly to institutions' (2013, 46). To this end, the DHET (2013, 47) proposes that 'in addressing disability, a holistic approach is necessary, taking into account the built environment as well as the use of specialised technology and assistive devices geared for people with disabilities' (2013, 47).

This chapter is divided into five sections. We start by theorising the notions of 'disabilities', 'inclusion' and 'exclusion'. Our view is that we cannot have a meaningful discussion if we cannot firstly have clarity on how we understand the above-mentioned terms, which are critical drivers of the chapter. Secondly, we explore the notion of ODL. This exploration is necessary given that we focus on learning opportunities for students with disabilities in an ODL environment. We sketch the ODL framework and raise critical questions whether ODL provides inclusive learning opportunities for students with disabilities. Thirdly, we briefly touch on the statistics of students with disabilities at the University of South Africa (Unisa) by race. Fourthly, we describe Unisa's Advocacy and Resource Centre for Students with Disabilities (ARCSWiD) with a view to ascertaining whether the ARCSWiD's initiatives measure up. In the fifth and final section we offer some concluding remarks.

## Disabilities, inclusion, and exclusion

In this section we clarify the key terms we shall use in the chapter, and demarcate how we understand them, and concomitantly how we shall use them.

### Disability

In their introduction to Disability and Social Change: A South African Agenda, Swartz and Watermeyer observe that 'our internal assumptions regarding what disability means, with their attendant ideas regarding what disabled people "need", or "should strive for", typically remain invisible and unquestioned within us until we are required to acknowledge and examine them' (2006, 2). In the same vein, Priestley (2006, 19) points out that 'the way we understand disability and the way we learn about it affect the way we respond to disabled people in society' (2006, 19). While Mutanga laments that:

> The problem with the current notion of inclusion in the higher education system is that students with disabilities are lumped together as a homogeneous group, [a]uthorities adopt a one-size-fits-all approach rather than realising that there's a difference between a wheelchair user and someone who is visually impaired. Students with disabilities are not all the same (2017, 30).

It is evident that disability is a complex and contested term that is understood differently by different sections of society. Tugli et al. argue that:

> Students with disabilities pose formidable challenges to higher institutions not only in terms of gaining physical access to buildings, but also in relation to much wider issues within the institutions. These wider issues include negative attitudes, lack of appropriate services, social integration, curricular barriers and progression (2013, 357).

In our effort to understand this seemingly illusive term, our take on the notion of disability shall draw on the definitions provided by the United Nation's Convention on the Rights of Persons with Disabilities (2006); the South African Department of Social Development's White Paper on the Rights of Persons with Disabilities (2016); the South African Department of Higher Education and Training's (DHET) (2013) White Paper for Post-School Education and Training, and the Office of South Africa's Deputy President's Integrated National Disability Strategy (1997). We shall exclude the Department of Basic Education's White Paper 6: Special Needs Education: Building an Inclusive Education and Training System (2001) for the simple reason that even though it 'provides a blueprint for inclusive education in South Africa as a means to address the challenge of disability across the education landscape' (DHET 2013, 44), its primary focus is schooling.

It is our view that the above-mentioned policy documents provide reasonable insights on how the notion of disability might be comprehended. For instance, in section (e) of its Preamble, the UN Convention on the Rights of Persons with Disabilities states that 'disability is an evolving concept…that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'. To that end, Article 19 of the UN Convention on the Rights of Persons with Disabilities requires its signatories to 'recognise the equal rights of all persons with disabilities to live in the community, with choices equal to others', and to 'take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'. Chapter 6 of the DHET's White Paper for Post-School Education and Training (2013) is appropriately titled 'Addressing disability'. In this paper, the DHET (2013, 45) notes that 'despite attempts to integrate disability into the broader policy arena, currently there is no national policy on disability to guide education and training institutions in the post-school domain'. The DHET (2013, 45) further notes that 'the management of disability in post-school education remains fragmented and separate to that of existing transformation and diversity programmes at the institutional level'. To that end, the Integrated National Disability Strategy states that 'disability tends to be couched within a medical and welfare framework, identifying people with disabilities as ill, different from their non-disabled peers, and in need of care'.

The Integrated National Disability Strategy notes that 'people with disabilities are excluded from the mainstream of society and experience difficulty in accessing fundamental rights'. To that end, the strategy advocates 'an integration of disability issues in all government development strategies, planning and programmes'. The strategy states that 'one of the cornerstones of disability policy is prevention. Most disabilities are preventable'. However, 'there is no coherent coordination between the various government departments to ensure that these policies are properly carried out'.

## Inclusion and exclusion

The concepts of 'inclusion' and 'exclusion' are closely related: one cannot be explained without the other. As Mutanga explains:

> [T]he concepts of inclusion and exclusion require closer analysis in order to understand who is excluded and who is making the inclusion decisions. This means that the creation of an equitable and just higher education system for disabled people should involve a more careful and rigorous process of enquiry into how these barriers emerge and are reproduced within HEIs (2015, 15)

Mutanga wants to push the debate on inclusion/exclusion further by asking ‘how disabled students are actually “doing” in higher education’ (2015, 14). He also wants us to think of inclusion ‘beyond enrolments of disabled students to what can be done to create and expand opportunities within higher education for disabled students to succeed’ (Mutanga 2015, 14). Soudien and Baxen (2006, 159) note that ‘discourses of inclusion and exclusion fail to specify the relationship between disability, race, class, gender and other forms of difference and inequality and fail to show how these fail to articulate with each other’; they argue that this is ‘the major problem with current approaches to dealing with disability’.

The Integrated National Disability Strategy states that the exclusion experienced by people with disabilities and their families is the result of a range of factors, such as the political and economic inequalities of the apartheid system; social attitudes which have perpetuated stereotypes of disabled people as dependent and in need of care; and a discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers. The Integrated National Disability Strategy’s delineation of exclusion of people with disability encompasses exclusion from social security benefits; exclusion due to unemployment; exclusion due to legislative failure to protect the rights of people with disabilities; and failure to remove barriers that prevent people with disabilities from accessing equal opportunities. This view is consistent with the view of the DSD’s White Paper on the Rights of Persons with Disabilities which states that ‘exclusion refers to the act of socially isolating or marginalising an individual or groups on the basis of discrimination by not allowing or enabling them to fully participate and be included in society and enjoy the same rights and privileges’ (2016, 7). The DSD further posits that such ‘devaluation of and exclusion of individuals or groups results in keeping “’others” outside from the prevailing social system and thus restricting their access to material, social, economic and political resources and rights’. Its view is that ‘exclusion consists of dynamic, multi-dimensional processes driven by unequal power relationships interacting across economic, political, social and cultural dimension and at different levels including individual, household, group, community, country and global levels’.

Similarly, but with reference to ‘inclusion’, Mutanga argues that ‘proper inclusion implies multidimensional support that is financial, social and academic, and must be supported by policies. It is not enough to regard physical access and the presence of students with disabilities as inclusive.’ (2017, 30). It is his view that ‘universities must move beyond measuring inclusion based only on the number of students with disability they have enrolled each year. Instead, they must work to create more equitable, just education for students with disabilities’.

Howell (2006, 164) argues that ‘disabled students in South Africa, particularly black disabled learners, have in the past been—and continue to be—especially vulnerable to exclusion from the education system, including the higher education system’. She opines that ‘for disabled students, inequalities in higher education begin with inequalities that have shaped the whole schooling system in South Africa’. She argues that ‘the limited provision that existed for disabled learners, especially black disabled learners, meant that among these learners there were very high levels of exclusion from the education system’ (Howell 2006, 165). Thus, for Howell, ‘the lack of appropriate and adequate provision for disabled learners at the schooling level has profoundly affected access to higher education for disabled people’. It is Howell’s (2006) contention that inherent inequalities in South African higher education constitute barriers to access for students with disabilities. She argues that ‘these barriers arise from the ways in which higher education institutions are structured and function, the dominant attitudes that inform and shape the practice of institutions, as well as the role that higher education plays within society as a whole’ (Howell 2006, 166). For instance, ‘on the basis of what is regarded as “reasonable” for institutions, disabled students are still being told that the institution is not equipped to provide them with the support that they require, and that it would thus be in the student’s interest to seek out alternatives’ (Howell 2006, 167).

## Open distance learning (ODL) and disability

Open distance learning (ODL) in global institutions such as Unisa; the Indira Gandhi National Open University (IGNOU) in New Delhi, India; the University of Phoenix, in Arizona, USA; and Athabasca University, in Alberta, Canada, brand themselves to the student clientele as *open*, *accessible*, *flexible*, *affordable*, and *supportive* (Letseka and Pitsoe 2014, 2013, 2012). Unisa states in its Open Distance Learning Policy that ‘open distance learning focuses on removing barriers to access learning, flexibility of learning provision, student-centeredness, supporting students and constructing learning programmes with the expectation that students can succeed’ (2008, 2). Letseka and Pitsoe (2012, 222) argue that:

> Presumed in this market discourse is the perception that mature adult working students take responsibility for their learning; they are capable of learning alone or in small groups; they can learn at their own pace and in their own time; they can learn from a variety of learning materials, including the use of audio-visual media; they are active rather than passive learners; they need less frequent help from their teachers; they therefore learn from other people besides their teachers, and that they are capable of doing a lot of self-assessment.

- Openness

The notion of openness in ODL institutions suggests that there are no barriers to entry. Commenting on the openness of the Open University, United Kingdom (OU UK), Gourley and Lane (2009, 57) argue that the OU UK “has no barriers to entry, no entry requirements—only exit standards. A person’s background and previous advantage or disadvantage is entirely irrelevant'. In the same vein, Johnson and Barrett (2003, 41) argue that '[t]he Open University has always been open in that it does not require previous educational qualifications to gain entry to its undergraduate courses'. They further argue that 'openness and student centeredness have been in place from the start of the Open University but so, also, have the needs of the learner' (Johnson and Barrett 2003, 42).

- Accessibility

ODL institutions provide access to education to adult working students who would not be able to obtain higher education qualifications were they left with full-time contact tertiary institutions as their only avenues for accessing higher education (Letseka and Pitsoe 2014, 9144). Perraton et al. (2001, 3) argue that 'ODL is an organised educational activity based on the use of teaching materials, in which the constraints on study are minimised in terms of access, entry, or time and place, pace, method of study, or any combination of these'. For Letseka (2016, 33), 'ODL institutions do not require students to be in the same space at the same time in order for learning to take place. Learning can take place at home, at restaurants, while travelling or while on holiday'.

- Flexibility

Unisa's view is that its open access policy provides opportunities while its materials, quality assurance and student support based on best practices in open and distance learning ensure success for the reasonably diligent student. In its Open Distance Learning Policy (2008, 2), Unisa states that its 'open learning' mode 'is an approach to learning that gives students flexibility and choice over what, when, where, at what pace and how they learn. Open learning is all encompassing and includes distance education, resource-based learning, correspondence learning, flexi-study and self-paced study'. The university's 'responsible open admission' is aimed at:

> Identifying potential and appropriate support for students. It constitutes competency evaluation and recognises students' educational background. It promotes equity of access and the provision of appropriate student support interventions aimed at bridging the gaps in students' academic and social readiness for higher education (Unisa 2008, 2).

- Affordability

Pityana (2009, 7) argues that 'in the developing world ODL is a promising and practical strategy to address the challenge of widening access, thus increasing participation in higher education. It is increasingly being seen as an educational delivery model which is cost-effective without sacrificing quality'. It is Pityana's view (2009) that on the African continent where resources are scarce and higher education provision is poor, ODL has been accepted as a viable, cost-effective means of expanding provision without costly outlay in infrastructure. Unisa's Strategic Plan: An Agenda for Transformation (2006, 2) states that it charges 'reasonable fees that make higher education more affordable'. It assures its student clientele that its 'affordable plan ensures that the university is in a strong position to deliver on its mandate to broaden access to previously disadvantaged students' (Unisa 2006, 9).

- Supportive

Letseka and Pitsoe (2012, 225) understand 'learner support in ODL to refer to meeting the needs of all learners through provision of quality'. In the same vein, Thorp (2002, 107) conceives of learner support in ODL as 'meeting the needs of all learners through provision of quality learning, guidance about course choice, preparatory diagnosis, study skills, access to group learning in seminars and tutorials, and so on'. Commenting on student support at the OU UK, Johnson and Barrett (2003, 41) argue that the university 'has always been understood that students need access not only to high quality course materials, but also to a wide range of support materials and strategies to enable them to become successful, independent learners in an increasingly complex system of open and distance education'. The OU UK (2012, 13) claims it uses:

> A system of *supported open learning* which includes the provision of high-quality print and multimedia teaching materials, together with personalised tuition, learning feedback and support. Personalised tuition takes the form of online and face-to-face tutorials, online forums, telephone and email tuition, and residential and day schools, depending on the module and qualification being studied.

However, and against the backdrop of a myriad concerns expressed above vis-à-vis the general lack of support for students with disability in higher education in general (Mutanga 2017; Mutanga 2015; Howell 2006; Priestley 2006; Soudien and Baxen 2006; Swartz and Watermeyer 2006), it seems prudent that we approach support for students with disability in ODL with circumspection.

## Statistics of students with disabilities at Unisa

With an estimated student enrolment in excess of 300 000, Unisa is without a doubt the largest university in Africa (Letseka and Koenane 2016; Letseka 2015; Letseka and Pitsoe 2014; Letseka and Pitsoe, 2012; Unisa, 2012). The number of students with disabilities in South Africa's higher education institutions is on the increase due to the institution's open access policies. Magongo and Motimele (2011) estimate that the number of students with disabilities at South Africa's HEIs is 2 188 456. In 2010, Unisa's Department of Institutional Statistics and Analysis (DISA) estimated that of the overall student population of 262 200, the number of students with disabilities stood at 1 982 (see Table 1). African students made up 50.8 per cent of this total, followed by whites (35, 0%), Indians (9, 2%), and coloured (5, 1%).

Tladi and Subotsky (2010) make the shocking revelation that regardless of the high number of black students with disabilities, the fewer in numbers white and the Indian students with disabilities tend to succeed more in higher education. They attribute this success to the fact that the latter group is generally less impoverished and likely to have better support from their families. Tladi and Subotksy (2010) also suggest that this group of students could be thriving because they have the required assistive technologies to access higher education. In the penultimate section below, we sketch the support initiatives of Unisa's ARCSWiD with a view to ascertaining whether the ARCSWiD measures up.

Figure 1: Distribution of Unisa Students with Disabilities by Race, May 2010

| | African | Coloured | Indian | White | Unknown | Total |
|---|---|---|---|---|---|---|
| Disable | 1 006 | 101 | 182 | 693 | - | 1 982 |
| | 50,8% | 5,1% | 9,2% | 35,0% | 0,0% | 0,8% |
| Without disability | 171 661 | 14 556 | 21 559 | 52 384 | 58 | 260 218 |
| | 66,0% | 5,6% | 8,3% | 20,1% | 0,0% | 99,2% |
| Overall student population | 172 667 | 14 657 | 21 741 | 53 077 | 58 | 262 200 |
| | 65,9% | 5,6% | 8,3% | 20,2% | 0,0% | 100,0% |

*Source: Unisa (2010) Department of Institutional Statistics and Analysis (DISA)

## Advocacy and Resource Centre for Students with Disabilities (ARCSWiD)

Unisa's support for students with disabilities is driven by the ARCSWiD unit, which is located in the office of the Dean of Student Directorate. ARCSWiD categorises student support into: student support and administration; advocacy and training; and academic support. Student support and administration assists students with completing application forms during registration, with fee reduction applications, by offering sign language and interpretation services to deaf students, and with other registration related matters. Once the students have been registered, blind and partially sighted students have their study materials converted to either braille, large-print, electronic or audio formats. Referrals to career and counselling services are made in order to ensure the students' holistic growth. In the case of new blind and/or partially sighted students, orientation and mobility assistance are provided during the first week at all Unisa campuses in order to enable the students to attain independence.

Furthermore, ARCSWiD provides advocacy and training on disability to enhance disability awareness among staff and students who will interact with students with disabilities. ARCSWiD supports staff and students with disabilities in terms of assistive devices and access to technology equipment. It also commissions and conducts research on disability in higher education with a view to promoting equitable access to higher education. Provision of academic support aims to enable students with disabilities to succeed in their studies. To this end, ARCSWiD provides academic support interventions in consultation with the academic departments. For instance, ARCSWiD monitors student performance in order to track those that might be at risk of failing modules. Once the risks have been ascertained, support mechanisms are developed in order to ensure that the students succeed. Similarly, when a student is hospitalised for lengthy periods, ARCSWiD arranges for that student to submit their assignments without a penalty for late submission. In the case of students who cannot access prescribed books and other reading material in standard print, ARCSWiD liaises with publishers to provide electronic versions. Since

Unisa students are geographically dispersed, their electronic books are electronically sent to them with the applicable copyright linked to their personal computer. As the students undertake formative and summative assessments in their preferred formats, ARCSWiD transcribes their assignments and examination scripts to standard print for the lecturer to access and back to the preferred format for the student to access.

## ODL and students with disability

ODL as an educational provision that allows students to learn from a distance is regarded as more suitable for students with disabilities (Ngubane-Mokiwa 2013). Its mode of learning allows students to learn from multiple geographical locations. Dhunpath and Dhunpath also echo this interventionist nature of ODL by saying that 'Unisa has a critical role to play in providing access through its ODL programmes, to those students who would otherwise be excluded from accessing higher education opportunities by conditions beyond their control' (2015, 106). Others have argued that ODL is an educational intervention as it allows people to pursue their educational goals while they are fully employed, travelling and taking care of their families (Guiney 2014; Newberry and DeLuca 2014).

Mgqwashu (2012, 208) argues that students require multiple skills which can enable them to read academic texts, make inferences and draw conclusions from their readings. This then questions what intervention ODL has to enhance learning (epistemological access) for students with disabilities. Unisa has an Academic Literacies Programme that uses contact classes in order to assist students to bridge the gap between their schooling and the university learning experiences. Because learners with disabilities usually receive a lower standard of schooling at 'special schools' (Howell 2005; Maguvhe 2015), most of them require maximum support when they embark on higher education. Pittman and Heiselt (2014) opine that there is an increase in the number of students with disabilities in distance education due to the heightened awareness of their right to education. The high numbers of students are usually not a challenge in the distance education environment as it is already geared to respond to economies of scale (Hülsmann 2013).

## Inclusivity in ODL

Inclusivity in the higher education context is aimed at promoting flexible, adaptive and authentic learning for all student populations (McLoughlin 2001). Slater, Pearson, Warren and Forbes (2015) posit that inclusivity is meant to improve accessibility and enhance the learning experiences of students with disabilities on equal terms with the learning experiences of students without disabilities. The OU UK (2013) commits to ensuring that its learning environment is inclusive. This is done through the Equality Scheme, which aims to meet the learning needs of all students. In the opening page, the OU UK's Equality and Diversity Interim Report (2013) states:

> We are creating an inclusive university community and a society—where people are treated with dignity and respect, where inequalities are challenges, and where we anticipate, and respond positively to, different needs and circumstances, so that everyone can achieve their potential.

Inclusivity eliminates discrimination in that it accommodates students' diverse needs. Mole (2013) argues that inclusivity has to be guided by institutional regulations and policies. Instead of having institutional policies that are vague and do not address specific spheres for students with disabilities, inclusivity should be aligned with registration, curriculum design, teaching and learning, student assessment, research, and student support policies. As Mutanga and Walker (2015, 503) point out, the stigma associated with having a disability and having to receive specialised accommodation is itself a barrier to inclusion. In the same vein, Terzi (2005) opines that the dilemma of difference reinforces discrimination by placing too much attention on disability or simply ignoring it. It is therefore critical that teachers realise the importance of developing inclusive teaching strategies (Lumadi and Maguvhe 2012; Jensen, McCrary, Krampe, and Cooper 2004).

## Conclusion

In this chapter, we have grappled with the challenge of learning opportunities for students with disabilities in ODL contexts, with specific reference to Unisa. We anchored our conception of disability in definitions drawn from the Department of Social Development's White Paper on the Rights of Persons with Disabilities (2016); the Department of Higher Education and Training's White Paper for Post-School Education and Training (2013); the University of South Africa's (Unisa) Open Distance Learning Policy (2008); Unisa's Strategic Plan: An Agenda for Transformation (2006); the United Nation's Convention on the Rights of Persons with Disabilities (2006); and South Africa's Office of the Deputy President's Integrated National Disability Strategy (1997). We argued that while 'disability' is an evolving concept about which there might not be consensus, our understanding is that it refers to a plethora of impairments, including, but not limited to, physical, psychosocial, intellectual, neurological and/or sensory impairments. We suggested that 'disability' should take centre stage against the backdrop of societies' failure to uphold the specific rights and needs of individuals with disabilities.

We argued that notwithstanding the above-mentioned battery of policies on persons with disabilities, in higher education in general, and in the ODL environment in particular, learning opportunities for students with disabilities are not assured. We attributed this lack of acknowledgement to the fact that students with disabilities account for less than 1 per cent of the total student population. We noted that HEIs tend to adopt a one-size-fits-all approach that treats students with disabilities as a homogeneous group. We noted the failure of the discourses of inclusion and exclusion to specify the relationship between disability, race, class, gender, and other forms of difference and inequality. We showed that the situation becomes dire for black disabled students who are particularly vulnerable to exclusion in their schooling years, which continues in the higher education system. We noted that while ODL institutions brand themselves as *open*, *accessible*, *flexible*, *affordable* and *supportive*, this branding discourse needs to be approached with circumspection in view of mounting concerns about the general exclusion of students with disabilities in higher education. We fleshed out Unisa's support initiatives through the Advocacy and Resource Centre for Students with Disabilities, and showed that ARCSWiD provides academic support interventions in consultation with the academic departments with a view to enabling Unisa's students with disabilities to succeed in their studies.

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# CHAPTER 4

## FUNDING AND INCLUSION IN HIGHER EDUCATION INSTITUTIONS FOR STUDENTS WITH DISABILITIES

Desire Chiwandire and Louise Vincent

### Abstract

Historically, challenges faced by students with disabilities in accessing higher education institutions (HEIs) were attributed to limited public funding. The introduction of progressive funding models such as disability scholarships served to widen access to, and participation in, higher education for students with disabilities. However, recent years have seen these advances threatened by funding cuts and privatisation in higher education. In this chapter, the funding mechanisms of selected developed and developing democratic countries, including the United Kingdom, the United States, Canada, Australia, South Africa and India are described in order to gain an insight into how such mechanisms enhance access, equal participation, retention, success, and equality of outcome for students with disabilities. The countries selected are often spoken about as exemplars of best practices in relation to widening access and opportunities for students with disabilities through government mandated funding mechanisms. A critical literature review was conducted of the sample countries' funding mechanisms governing students with disabilities in higher education and other relevant government documents; secondary academic literature on disability funding; online sources, including University World News, University Affairs, newspaper articles, newsletters, literature from bodies such as the Organisation for Economic Co-operation and Development, Disabled World and Parliamentary Monitoring Group. Data were analysed using a theoretically derived directed qualitative content analysis. Barriers which place students with disabilities at a substantial educational disadvantage compared to their non-disabled peers include bureaucratisation of application processes, cuts in disability funding, means-test requirements, minimal scholarships for supporting part-time and distance learning

for students with disabilities and inadequate financial support to meet the day-to-day costs that arise as a result of disability. Although the steady increase of students with disabilities accessing HEIs of the sampled countries has been attributed to supportive disability funding policies, notable is the fact that these students are still confronted by insurmountable disability funding-oriented barriers. Thus, we recommend the need for these HEIs to address these challenges as a matter of urgency if they are to respect the rights of students with disabilities as well as provide them with an enabling environment to succeed academically.

## Introduction

In the 1980s and 1990s, segregation of students with disabilities from mainstream education was called into question by the inclusive schools movement (Simons and Masschelein 200, 217). These developments culminated in the 1994 Salamanca World Conference on Special Needs Education, which was attended by 300 participants from 92 countries and 25 international organisations. The gathering led to the signing of the Salamanca Statement on inclusive education, which states that:

> Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all (UNESCO 1994, ix).

Following the Salamanca Statement, inclusive education has been widely accepted as a model for education (Maher 2009). Proponents see inclusive education as foundational to a more just society (Ainscow et al. 2004), because it obliges mainstream educational institutions to focus on increasing the participation and levels of attainment of students with disabilities as a historically marginalised group (Wolanin and Steele 2004, vii).

The Salamanca Conference highlighted the need to prioritise funding as a mechanism for fostering the inclusion of students with disabilities in higher education and encouraged the international community to:

> Give the highest policy and budgetary priority to improve their educational systems to enable them to include all children regardless of individuals' differences and difficulties (UNESCO 1994, ix).

Recent literature on funding mechanisms aimed at providing access to higher education for previously excluded constituencies has mainly taken the form of comparative case studies (Yang and McCall 2014). None of these studies has focused specifically on students with disabilities. Yet, the latter have very particular individual funding needs depending on the type or severity of disability. As a result of their varying and varied needs, students with disabilities differ with regard to the nature of the support they require to function optimally in their everyday living and learning environments. In other words, while the overarching question of higher education funding is a burning one, students with disabilities cannot simply be addressed as part of the wider debate.

Moreover, as many scholars have pointed out, universities globally are experiencing a dramatic decline in government subsidies and an increase in student fees (De Jager and Gbadamosi 2010, 254) which have negatively impacted on the functioning of universities. In 2014, Hoareau McGrath and colleagues conducted a comparative study which analysed admission systems to higher education across ten European Union (EU) member countries focusing on how these countries deal with the inclusion of students with disabilities (Hoareau McGrath et al. 2014, 5). The study found that cutbacks in these countries' public funding resources reduced or negatively impacted on equity in admission to higher education for many students, including those with disabilities in these countries (Hoareau McGrath et al. 2014, 9).

What follows is an attempt to describe disability funding mechanisms and approaches employed in a sample of democratic states both in the Global North and the Global South to gain an insight into how such mechanisms do or do not enhance access, equal participation, retention, success, and equality of outcome for students with disabilities. The sampled countries represent a diversity of Global North and Global South examples, all of which have in common that they are signatories to the 2006 United Nations Convention on the Rights of Disabled Persons (UNCRPD), which obliges member states to ensure an inclusive education system at all levels, including higher education, and to provide reasonable accommodations (RAs) and appropriate support services tailored to individuals' educational needs as a measure for ensuring that persons with disabilities can participate effectively in a free society.

These countries have each enacted non-discriminatory legislation and have put in place disability funding policies and mechanisms to facilitate the inclusion of students with disabilities in higher education institutions (HEIs), and to address their educational needs. The selected countries take a human rights-based approach, which prohibits discrimination against students with disabilities on the grounds of disability and this is also provided for, in most instances, in these countries' constitutions. As democracies, the countries surveyed draw on a mix of principles of social justice, equality, widening participation, redress, equality of access, transformation, affirmative action principles, equality of opportunity and equity in their approach to promote access, retention and success in higher education for students with disabilities. Research on funding of disability in HEIs has taken a dichotomous form with the Global North countries on the one hand being associated with having progressive policies and practices which enable them to meet best practices criteria (Eleweke and Rodda 2002).

In contrast, developing countries, or the Global South, have been discussed as either struggling or failing to meet these criteria because seldom do their governments and HEIs prioritise expenditure on inclusive education oriented initiatives, including funding regarding disability (Eleweke and Rodda 2002). South Africa and India fall into the category of Global South countries. We compared South Africa and India with Global North countries because the two countries share the characteristic of being 'countries in transition' while at the same time being regarded as evincing best practices regarding disability inclusion compared to other Global South countries.

Drawing on a directed content analysis of policy and other documents, the chapter argues that availability of adequate funding to HEIs to support students, including those with disabilities, is central to the maintenance and enhancement of quality education (Daugherty et al. 2013, 39). However, in the wake of government funding cuts, the privatisation of HEIs and overreliance on private sources to finance higher education, the trend is towards universities adopting selective inclusion of students with disabilities based on cost rather than on the principles of inclusion, access and equal chances of success for all.

## The study

Bowen describes document analysis as 'a systematic procedure for reviewing or evaluating documents—both printed and electronic' (2009, 27). As a qualitative analytical research method, document analysis 'requires that data be examined and interpreted to elicit meaning, gain understanding, and develop empirical knowledge' (Bowen 2009, 27). For the purpose of this study, the following documents were reviewed: the UNCRPD and the 1994 Salamanca Conference documents; peer-reviewed articles on inclusive education and disability in higher education; reports on disability retrieved from the official websites of the World Health Organisation (WHO), the United Nations Educational, Scientific and Cultural Organisation (UNESCO), and the Organisation for Economic Co-operation and Development (OECD); and articles from *Disabled World*, *University World News* and *Times Higher Education*. Documents specific to the countries in the sample included:

> South Africa—White Paper 3 on Higher Education Transformation; the 1997 White Paper on an Integrated National Disability Strategy; the 1997 Higher Education Act; the 2001 National Plan for Higher Education and the 2001 Education White Paper 6, Special Needs Education: Building an Inclusive Education and Training System and national newspaper articles on the National Student Financial Aid Scheme (NSFAS).
>
> India—the Equal Opportunities, Protection of Rights and Full Participation (PWD) Act and the Higher Education for Persons with Special Needs (HEPSN) policy as retrieved from University Grants Commission official website.
>
> United States—Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA); various policy documents reporting on the country's federal student aid programme, known as the Pell Grant Program; various OECD reports on the inclusion of students with disabilities in higher education and other reports from the US Department of Education.
>
> Australia—the document known as 'A Fair Chance for All', which aims to increase the enrolments of students with disabilities in Australian higher education as well as the 1992 Disability Discrimination Act (DDA) and various OECD reports on the inclusion of students with disabilities in higher education as well as national newspaper articles reporting on issues relating to the Disability Support Program (DSP), the Australian funding scheme for students with disabilities.
>
> Canada—the Canadian Human Rights Act (CHRA) and the Canadian Charter of Rights and Freedoms (CCRF); the Canada Student Grant for Services and

Equipment for Students with Permanent Disabilities (CSGSESPD) and the Canadian Province of Ontario Bursary scheme for Students with Disabilities (BSWD) as well as OECD reports on the inclusion of students with disabilities in higher education retrieved from the Ontario Human Rights Commission website.

United Kingdom—the Equality Act, 2010; OECD reports on the inclusion of students with disabilities in the UK higher education system; newspaper articles reporting on the country's various disability funding schemes; documents relating to the Disabled Students' Allowance (DSA) grant; Premium Funding and the Higher Education Funding Council for England (HEFCE) Student Opportunity funding.

## Findings

Table 1: Summary of findings

| Country | Supporting policies | Funding mechanisms | Coverage extent | Limitations | Current challenges |
|---|---|---|---|---|---|
| United Kingdom | Equality Act (2010) | Premium Funding, Student Opportunity funding | Assistive technology | No personal assistant<br>Coverage | 2015 cut in disabled students funding<br>Disproportionally affect smaller<br>HEIs in comparison to bigger ones<br>Overreliance on private funding as a source of HEI income |
| USA | Americans with Disabilities Act (1990); Rehabilitation Act (1973) | Pell Grant Program | Assistive technology | - | 2009 Federal cuts; Increased tuition fees |
| Canada | Canada Charter of Rights and the Canadian Charter of Rights and Freedoms (CCRF) | Canada States Grant for Services and Equipment | Assistive technology | No tuition, tools, general core requisition coverage | - |
| Australia | A Fair Chance for All (1990) | Disability Support Programme | Assistive technology, Sign language support provided | - | - |

| | | | | | |
|---|---|---|---|---|---|
| South Africa | National Plan for Higher Education, 2001), DOE (1997), DHET (2012) | NSFAS | Tuition, assistive technology | No sign language support<br>No personal support coverage | Decline in funding |
| India | Equal opportunities protection (1995)<br>Persons with Disabilities Act (1995) | | Assistive technology | | Decline in funding |

## Sampled countries’ funding trends

The inclusion of students with disabilities in the UK HEIs is currently facilitated by the Equality Act, 2010 (c. 15). Chapter 2 of the Act prohibits discrimination against persons with disabilities in all spheres of their lives including in higher education. Disability policies are not only aimed at widening access to higher education but also at promoting success in higher education for students with disabilities. Widening participation is conceptualised as ’opening higher education up to people who might not traditionally have considered university while improving retention, because students from different backgrounds need different support to complete their courses successfully’ (Bourn 2007). To achieve these goals, the Higher Education Funding Council for England, for example, enjoins:

> All higher education providers and stakeholders [*to*] take a broad view of widening participation to encompass a student’s entire lifecycle: preparing for and entering higher education, graduating successfully, and progressing to employment or postgraduate study (Department for Business, Innovation and Skills 2014, 9).

The UK’s higher education funding model for students with disabilities draws mainly on the principle of ‘equality in access to education’ (Tumelty 2007) irrespective of “a person’s age, ethnicity, gender, disability and/or social background; (Department for Business, Innovation and Skills 2014, 7). The inclusion of disabled students in higher education has been supported by a number of measures, including the non-means tested DSA grant, which:

> Provides extra financial help if you have a disability or a specific learning difficulty like dyslexia. This is paid on top of the standard student finance package and does not have to be repaid (*Disabled World* 2016).

Full-time, part-time, and postgraduate students can apply for DSA. Premium Funding is a funding allocation to HEIs to facilitate access for students with disabilities (Research Briefing 2008, 2). Through Student Opportunity funding, the HEFCE also provides funds to HEIs in recognition of the additional costs of recruiting, supporting, and retaining students with disabilities (OECD Higher Education Programme IMHE 2014, 20).

In the USA, Congress enacted section 504 of the Rehabilitation Act of 1973 as a measure to prohibit 'discrimination against otherwise qualified persons with disabilities in any program receiving federal funds' (Wolanin and Steele 2004, 53). Section 504 prohibits denial of admission to a person because of their disability (Wolanin and Steele 2004, 34). With the passage of the Rehabilitation Act of 1973, which defined facilities that are 'inaccessible to or unusable by handicapped persons' to be a form of prohibited discrimination, incentives were put in place in the form of federal funding to HEIs to enable them to make their facilities such as lecture theatres accessible to students with disabilities (Wolanin and Steele 2004, 34).

The Americans with Disabilities Act of 1990 (ADA) played an important role in enhancing the inclusion of students with disabilities by prohibiting discrimination against these students on the grounds of disability.

Under the ADA, discrimination against students with disabilities in American HEIs in relation to recruitment and admissions, academic and athletic activities, student examinations and evaluations, housing, financial aid, counselling, and career planning and placement are unconditionally prohibited (Kalivoda and Higbee 1994, 133). The ADA also provides for the accessibility of the built environment by requiring public and private HEIs that are recipients of state or federal funds to adopt 'accessible design of public places and facilities for all people, making buildings and facilities easily accessible to people with disabilities' (Wolanin and Steele 2004, 54). The education of students with disabilities is financed by a federal student aid programme, known as the Pell Grant Program, which supports eligible full-time students with disabilities (Wolanin and Steele 2004, ix–x). These students can apply for bursaries, non-repayable grants, loans or state or federally funded allowances managed by individual universities (OECD 2011, 54).

Canada has taken a human rights approach to fostering the inclusion of students with disabilities (Thomas 2012, 58–59) as is reflected in the CHRA principle that all individuals, including persons with disabilities, should have equal opportunities, and by prohibiting discrimination on the basis of disability (UNESCO 2015, 37). In particular, the Act prohibits the denial of education to persons with disabilities on the grounds of a disability as both discriminatory and illegal (UNESCO 2015, 37). Section 15 of the CHRA provides for 'equality of all people under the law and protection of individuals against discrimination on the basis of disability' (Roeher Institute 1996). The CCRF states that '[e]very individual is equal before the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on…mental or physical disability' among other grounds (UNESCO 2015, 37).

The Canada Student Grant for Services and Equipment for Students with Permanent Disabilities (CSGSESPD) is a non-repayable grant designed to support students overcome educational disability-related barriers that they may encounter while pursuing post-secondary training (Department of Workforce and Advanced Learning Student Financial Services (DWALSFS) 2016, 2). Eligible students under this programme 'may receive funding of up to $8000 to cover the costs of needed goods and/or services that are directly related to overcoming the educational barriers that the disability may present' (DWALSFS 2016, 2). Goods and/or services covered by the grant include, for instance, 'tutors;

specialised transportation (to and from school); note takers; interpreters; attendant care for studies; readers; alternate format; reimbursements for learning disability assessments; assistive technology' (DWALSFS 2016, 2). The Canadian Province of Ontario BSWD provides non-repayable financial assistance 'to assist students in meeting additional costs of equipment and supplies related to their participation in post-secondary education, which the student must incur because of his or her disability' (Ontario Human Rights Commission 2016).

It is worth noting that 1990 saw the Australian government target widening of access to HEIs for students from deprived socioeconomic backgrounds (including students with disabilities) in its policy document 'A Fair Chance for All' (Department of Employment, Education and Training (DEET) 1990). The stated rationale was:

> To ensure that Australians from all groups [*including students with disabilities*] in society have the opportunity to participate successfully in higher education. This will be achieved by changing the balance of the [university] student population to reflect more closely the composition of society as a whole (DEET 1990, 8).

The aim of 'A Fair Chance for All' were twofold: Firstly, 'to double the present commencing enrolments of people with disabilities by 1995' (Department of Employment, Education and Training (DEET) 1990, 40); and secondly, to ensure the participation with success of students with disabilities by making it 'unlawful [for] the development or approval of curriculum that excludes people with disabilities from participation' (Brett 2010, 4–5). Subsequently, the DDA of 1992 was passed, which obliges the Australian government to support the participation of all persons with disabilities at all levels of education including making it unlawful to exclude students with disabilities from universities on the grounds of disability (MacLean and Gannon 1997, 217).

Following South Africa's first democratic election in 1994, the policy context changed rapidly in support of increasing and broadening access to university study as one aspect of redressing past inequalities (Cloete 2002). This commitment to equity and access was reflected in policy documents of the time (DOE 1997; Ministry of Education 2001) and continues to be emphasised in more recent policy making (DHET 2012; National Planning Commission 2011).

During apartheid, black South African learners with disabilities were low on the priority list of the National Party government (Fagin 2011, 7). The 1948 Special Schools Act (SSA) provided for a segregated education system, which categorised children with disabilities according to both race and disability (Muthukrishna and Schoeman 2000), which made it difficult for learners with disabilities to access HEIs. The post-apartheid African National Congress (ANC) government's early policymakers developed several higher education policies aimed at 'putting in place appropriate redress strategies for the past inequities of the apartheid era' (Mapesela and Hay 2005, 112) aimed at radical transformation of South Africa's higher education environment (Badat 2010, 2). 'Transformation', thus, became a shorthand term to encapsulate a variety of initiatives aimed at 'removing barriers and providing access to higher education for black students, disadvantaged groups, and women' (Belyakov et al. 2009, 1).

South Africa's post-1994 higher education disability policies (see, e.g., the 1997 White Paper 3 on Higher Education Transformation; the 1997 White Paper on an Integrated National Disability Strategy; the 1997 Higher Education Act; the 2001 National Plan for Higher Education and the 2001 Education White Paper 6, Special Needs Education: Building an Inclusive Education and Training System) draw from the country's constitution in their emphasis on the need to address the disadvantages that persons with disabilities experienced in the past and continue to experience, and the need to prioritise funding of higher education opportunities for students with disabilities in the present. Education White Paper 3 called for the establishment of a new funding mechanism to achieve the principles of equity and redress through the abolition of all forms of discrimination, including on grounds of disability through empowerment measures, 'including financial support to bring about equal opportunity for individuals and institutions' (DOE 1997, 7–8). The 1996 Green Paper proposed the implementation of 'funding mechanisms that will embody the principles of affordability, sustainability and shared costs, as well as those of equity, redress, development, democratisation, effectiveness and efficiency' (DOE 1996, 6). The National Plan for Higher Education calls on HEIs, through their institutional plans and strategies, to commit themselves to increase access for people with special education needs (Ministry of Education 2001, 41). These policies have been applauded as 'the best in the world, meeting internationally acclaimed standards' (Mapesela and Hay 2005, 112).

In 1996, the National Student Financial Aid Scheme (NSFAS)—a student loan scheme with the intention of funding needy but capable students in higher education—was established (Cele and Menon 2006, 43). NSFAS caters for students with disabilities with a NSFAS bursary scheme tailored to giving non-means tested financial support to students with disabilities to study at one of the country's 23 public HEIs in South Africa (National Student Financial Aid Scheme 2012a, 3). Through the NSFAS scheme, the government:

> Intended to open opportunities in higher and further education and training and provide the necessary additional teaching and learning (curriculum) support for students to overcome any barriers to learning which have resulted from their disability (NSFAS 2012a, 3).

Drawing on United Nations (UN) reports, Thomas (2012, 59) has singled out India as 'ha[ving] the best disability policies among the developing countries. India has committed considerable financial resources to the implementation of inclusive education at primary, secondary and higher education levels' (Thomas 2005). The education of students with disabilities is regulated by the 1995 Equal Opportunities, Protection of Rights and Full Participation (PWD) Act, which prohibits discrimination in every sphere on the grounds of disability (Thomas 2005).

Impact of disability policies on increasing the numbers of students with disabilities in higher education

The general consensus within the reviewed literature in sampled countries is that these sampled countries' funding mechanisms have positively resulted in a steady increase of students with disabilities in HEIs. In the UK context, for instance, it is worth noting that since 1997, the HEFCE has been instrumental in providing specific funding to HEIs to assist with the costs of delivering quality education for students with disabilities (Department for Business, Innovation and Skills 2014, 64). In 2006–2007, for instance, it is estimated that the Funding Council allocated £13 million to HEIs to support in meeting additional costs in recruiting and retaining students with disabilities who are recipients of the DSA (National Audit Office 2008, 6). In 2012–2013 alone:

> Nearly £150 million was spent on DSA for some 60 000 students providing a range of specialist equipment, such as computer software for those with dyslexia, as well as modifications to accommodation and extra support to disabled students (*Times Higher Education* 2015).

In 2013–2014, £15 million was delivered by the HEFCE through its mainstream disability allocation, that is, around 4.5 per cent of the total 2013–2014 HEFCE targeted allocations for widening participation and improving retention, which was £332 million (Department for Business, Innovation and Skills 2014, 64). Disability funding has resulted in most UK universities successfully supporting the inclusion of students with disabilities, particularly those which have adopted ‘an inclusive model that seeks to ensure all aspects of the institutional offer are accessible to disabled students’ (Department for Business, Innovation and Skills 2014, 64). Against this background, Bourn (2007) has attributed the increase in the number of students declaring a disability entering higher education by over two-thirds between 2000–2001 and 2005–2006, from 82 000 to 138 000, to the DSA, as these students were DSA recipients.

Research in the USA has shown that as a result of supportive funding mechanisms, the number of students with disabilities in HEIs tripled over the past 20 years (Myers 2008). Pell Grant awards, for instance, amounted to some EUR 15 million in 2009 (OECD 2011, 54). The passage of anti-discriminatory legislation in the 1990s in Canada facilitated inclusive education, and changes in the attitudes of Canadian society. The number of students with disabilities attending post-secondary education increased steadily. For instance, the OECD estimated that in Canada’s Ontario province the enrolment of students with disabilities increased from 1668 in 1989–1990, to 6883 in 2000–2001 (OECD 2003). While in 1995 a mere 0.25 per cent of students with disabilities registered to receive disability-related services in 47 Canadian universities, in 2003 this percentage had increased to 5.67 per cent (Fichten et al. 2003). From 2001 to 2013, education rates of Canadian individuals with disabilities increased by 12 per cent, with 74.6 per cent of working-age adults with disabilities obtaining a high school diploma or higher educational certification (HRSD 2013).

Because of expansive financial support provided to students with disabilities, Australia experienced increased enrolment of students with disabilities in higher education, with students with learning disabilities being the largest enrolment group (Noble 1993). In 2012, nearly 6000 students with disabilities accessed equipment and educational support made available by Australian universities using DSP funds (OECD Higher Education Programme IMHE 2014, 4). In 2014, under the DSP, $6.9 million was made available to universities for this purpose.

The introduction of the NSFAS scheme in South Africa has translated into many visible changes in the sector as evidenced by the increase in the number of students with disabilities enrolling in HEIs (Wilson-Strydom 2015, 144). In the 2011 academic year alone, government earmarked R76.8 million 'to increase the funding available to students with disabilities and learners with special needs' (*University World News* 2011). According to information recorded in the Higher Education Management Information System (HEMIS), this allocation of R76.8 million subsequently saw an increase in the 'number of enrolled students with disabilities from 5856 in 2011 to 7110 in 2013' (Hammond 2015). Through NSFAS, R45.5 million in bursaries went to 1368 students with disabilities in 2012, and R69.9 million benefited 1383 students with disabilities in 2014 (Hammond 2015).

India has also witnessed a significant increase in the number of students with disabilities in HEIs, which many attributed to the policy of inclusive education backed by the availability of financial support (Shenoy 2011). These policies include the Persons with Disabilities Act (1995), which 'came into action by bringing into sharp focus the state's responsibility to empower the disabled with equal opportunities, protection of rights and full participation in the country's development process' (The Tenth Five Year Plan 2002–2007, 471). The Act obliges HEIs to provide equal access and proportionate opportunities to excel in education at all levels (Pillai 2012). Proponents have applauded the Act for its adoption of an affirmative action approach (Kumar 2012). Section 39 aims to achieve the goal of increasing access to education for students with disabilities through mandating all public HEIs that are government aided to reserve a 3 per cent quota for students with disabilities (Krishnan 2012).

Students with disabilities enrolling in Indian colleges are exempted from paying fees if they are not able to obtain financial assistance, and each university receives a one-time grant of 1 000 000 Rupees as an incentive for enrolling the maximum number of students with disabilities (Jameel 2011). The HEPSN scheme established by the Indian government provides grants to support the setting up of Disability Units in universities on condition that the applying university has a sufficient number of students with documented disabilities (Krishnan 2012). Angela Kohama has argued that India's Persons with Disabilities Act 'functioned as a catalyst for several other development projects around inclusion and disability' (Kohama 2012, 21–22). In addition to the HEPSN scheme, provisions have been made for 'incentives such as scholarships, both domestic and overseas to the students with disabilities with good academic records in higher education' (Jameel 2011, 6).

## Impact of sampled countries' funding mechanisms

Global research on retention has pointed to the availability of adequate financial aid as one of the most important determining factors when it comes to low-income and minority students enrolling in, and persisting to, degree completion in HEIs (Swail 2004). As a number of studies have shown, funding is critical to the challenge of increasing enrolment of students with disabilities in HEIs (Jameel 2011; Katsui 2009; Research Briefing 2008). Prior to the 1970s, many students with disabilities, both in developed and developing countries found it difficult to access higher education unless they had considerable personal means at their disposal (Kamalam et al. 2004). Availability of funding resulted in ‘disabled people increasingly hav[ing] access to educational opportunities that were not available to them in the past’ (Foley and Ferri 2012, 192).

The growing proportion of students with disabilities enrolled in OECD countries’ higher education has been attributed to the introduction of financial incentives resources provided to HEIs (OECD 2003), which ‘offset the additional costs that the presence of a student with special education needs may represent for the institution’ (OECD 2011, 55). It has been seen that the sample countries’ response to prioritising increasing access to HEIs for students with disabilities gained momentum in the early 1990s following the 1998 UNESCO World Conference on Higher Education leading to global international calls for greater ‘equality of access’ (UNESCO 1998).

Although all the sampled countries have supportive disability policies, however, in practice these countries are struggling to meet the goals outlined in their policies. As for the UK, an overall increase in reliance on private funding as a source of HEIs’ income (European Union 2014) and cuts to DSAs have resulted in students with disabilities being in debt, and care cuts resulting, for example, in students with disabilities not having access to a personal assistant to make it physically possible to get to lectures (Ryan 2017). Cuts to DSAs were first proposed in 2014 when David Willetts, then Universities Minister, announced a change in approach to the funding of computer equipment, software and consumable items through DSAs (Dunn 2016). In September 2015, the UK government officially confirmed that it would reduce direct public support for students with disabilities by making £30 million in cuts to DSA funding for students with disabilities in higher education (Dunn 2016). Willets urged universities to provide the support that was once provided by the DSA but without any funding allocated to cover the cost of this support. In other words, without allocated funding, universities are expected to pick up the tab for items that the DSA used to cover, including, for instance, ‘funding the provision of non- medical support staff, such as scribes, note takers, readers, proofreaders and sign language interpreters’ (Dunn 2016). A particular worry is that these cuts to the DSA will disproportionately affect smaller institutions, which may lack the resources to fund adequate support for students with disabilities. The National Union of Students (NUS) protested against the government’s intentions to cut funding when it was first announced in June 2014 and branded them as ‘arrogant and out of touch’ (*Times Higher Education* 2015) with recent figures showing that approximately 70 000 students would be affected (Dunn 2016). The announced changes to the DSA will undoubtedly jeopardise access and success for students with disabilities (Government United Kingdom 2016). Given that one of the core services being targeted is funding for assistive technology, such as laptops with specialist digital voice recording, it has been argued that students with a specific learning disability, like dyslexia, will be notably affected by this move, as these students rely most on a range of specialist equipment (*Times Higher Education* 2015).

However, the US recession of 2007 to 2009 saw federal cuts and some universities increasing their tuition fees (Camera 2016). The US HEIs face the challenge of ‘programs that should cooperate and coordinate to the benefit of students with disabilities often [*competing*] with each other to the detriment of these students’ (Moore 2003, 9–11). Growing numbers of students with disabilities pose a huge challenge primarily to HEIs whose federal funding campus-based programmes, such as Perkins Loans, Supplemental Educational Opportunity Grants and College Work Study, are inadequate, because the demand for funds far exceeds the available funds (Wolanin and Steele 2004). Despite the obligations imposed by the Rehabilitation Act of 1973 upon HEIs in relation to RAs for students with disabilities, in the context of budget constraints, many institutions object strongly to the cost of compliance (Scotch 2001).

In the Canadian context, there are limitations. While in terms of the CSGSESPD grant, recipients receive up to $8000 to cover the costs of academic-oriented needs, ‘the grant cannot be used to cover the cost of tuition, books, or items that are considered general requirements for the program’ (DWALSFS 2016, 1), which means that these students have to pay out of pocket for these costs. Similarly, financial assistance provided under the BSWD is restricted to purchasing specialised equipment and services required for participating in higher education studies and not RAs related to tuition, books and housing expenses, which are the obligation of HEIs (Ontario Human Rights Commission 2016). In 2016, although the federal budget allocated $118.2 million over two years for students with a disability, the funding targeted schools and saw cuts of $152.2 million over four years to the Higher Education Participation Program, which funds Canadian ‘universities to bring in students from the lowest socio-economic levels [including students with disabilities]’ (Ryan 2017).

In Australia, the DDA regulates how RAs should be applied in higher education environments, and places ‘a duty on institutions to make reasonable and anticipatory adjustments for disabled students in relation to teaching, learning and assessment’ (Research Briefing 2008, 2). Services supported by the DSP include production of course materials and lecture notes in braille, assistance with examinations and other assessment tasks and ‘purchase of adaptive software and/or adaptive computer equipment such as adaptive keyboards, mouse, screens, etc.’ (OECD Higher Education Programme IMHE 2014, 4). The passage of Australia’s DDA Standards for Education of 2005 saw the introduction of equity standards for the elimination of discrimination against persons with disabilities in terms of their access to services and education (DSD, DWCPD and UNICEF 2012).

In South Africa, public HEIs’ budgetary constraints dating back to the late 1990s have inhibited the achievement of these aspirations: ‘university funding declined in terms of the proportion of total state finance committed to higher education from 4 per cent in 1999 to 2.5 per cent in 2007 forcing universities to raise tuition fees sharply’ (Shrivastava and Shrivastava 2014, 815). Although ‘NSFAS will aid well over 400,000 students on a budget of R15-billion this year, [2017]’ (Collins 2017), nothing has been said yet as to whether the government will make similar increases to funding for students with disabilities. National Student Financial Aid Schemes students with disabilities recipients increased from 701 in 2004 to 1112 in 2007 and dropped to 649 in 2009 (NSFAS 2012b). Delays of NSFAS bursaries reaching students with disabilities negatively resulted in many of these students dropping out (DHET 2009). South African HEIs’ Disability Units have an obligation to provide sign language interpreters to support with the inclusion of students who are deaf, but this is a costly option resulting in institutions resorting instead to purchasing assistive devices, which is not the optimal outcome for these students.

South African students who are deaf are currently facing the challenge of the unavailability of professional South African sign language interpreters, which has forced these students to rely on ‘fake’ sign language interpreters who also ‘take advantage of deaf students, because they are desperately in need of access to education and will not complain about the lack of good sign language skills from the interpreters' (DHET 2015, 10). A 2011 study that sampled Disability Unit staff from 15 South African HEIs (FOTIM 2011) highlighted the fact that students who are deaf and hearing impaired who were NSFAS funding recipients expressed concerns over insufficiency of funding which forced them to resort to additional sources such as disability grants and parents' contributions as a way of supplementing their funding (FOTIM 2011). The study also found that disability bursaries and scholarships often do not cover personal needs such as caregivers, for example, for quadriplegics (FOTIM 2011).

In India, research indicates that advances in access and equity are threatened by steadily declining financing of HEIs by the Indian government since the mid-1990s, which has resulted in higher education increasingly being 'financed by non-government money, including household expenditures, fees, student loans, and voluntary contributions' (Prakash 2007 cited in Yang and McCall 2014, 28). These challenges which continue to be faced by the sampled countries clearly shed light on the fact that the mere provision of funding does not guarantee success once students with disabilities are enrolled (Belyakov et al. 2009). As defined by Belyakov et al., 'access with success goes a step further, defining true access as completion of a degree or certificate program that prepares one for a vocation' (Belyakov et al. 2009, 1–3). The provision of funding alone does not result in the realisation of meaningful inclusive education (Ferguson 2008). Access and presence in 'mainstream' classrooms and schools are a necessary—but clearly not sufficient—step towards inclusive education for students with disabilities.

## Discussion

As Bowen (2009) points out, document analysis can provide a means to track change and historical processes. Here, we track a process of the countries selected for review putting in place funding mechanisms and policies, leading to an increase in the participation rate in higher education of students with disabilities, followed by subsequent funding cutbacks and the privatisation and marketisation of higher education leading to the erosion of some of these gains. In the context of budget constraints, we see a pattern of HEIs falling back to a position of minimal accommodation for students with disabilities and an approach of minimal legal compliance rather than seeing their responsibility as extending to the fullest possible realisation of the equal right to access and success of students with disabilities.

A comparative analysis of the sampled countries' funding mechanisms shows that these countries have had considerable successes in relation to increasing access to higher education for students with disabilities. However, declining government support for education has led to a massive rise in the for-profit education industry, which has influenced the way in which universities set their funding priorities (Kenway et al. 1993) and has resulted in 'an ideological shift towards higher education as a private rather than a public good' (Meek 2000, 24). In the words of Newman and Jahdib (2009, 1), this has led to 'a paradigm shift' in the form of the 'so-called marketisation of education'. According to De Jager and Gbadamosi (2010, 254), the marketisation of higher education has resulted in 'a more competitive educational environment' in which universities compete with one another 'for students, resources and prestige' (Meek 2000, 23), and in which students are framed as consumers of education (Molesworth et al. 2009). These shifts have taken their toll on social inclusion initiatives. This is not a phenomenon of the developed world alone. Government funding cuts lead to rising operational costs, hiring freezes and large classes (Shrivastava and Shrivastava 2014)—all of which have the potential to negatively impact the inclusion of students with disabilities.

While all the countries surveyed here are signatories to the UNCRPD of 2006 (DSD et al. 2012), the economic context impinges on their ability to fulfil their obligations in terms of the Convention, not only with respect to the provision of funding to afford access to higher education for students with disabilities, but also to cover expenses such as 'auxiliary aids to provide accommodations to students with disabilities' to achieve 'a level playing field' in higher education (Wolanin and Steele 2004, 58).

Reliance on private rather than public funding has seen most universities breaching these obligations and serving market-driven, rather than public interests in relation to human health, safety or wellbeing (Côté-Boucher 2010). The consequences have proved detrimental to students with disabilities as their HEIs lose autonomy to private funders. Elaborating on this, Jung (2003) argues that this has resulted in universities fulfilling only their most 'minimal' legal and moral obligations to provide RAs to students with disabilities—principally disability accommodations necessary for their successful participation in the classroom. By relying on private funding sources, institutions are limited to the restrictions that come with donations—with private funders, for example, regarding personnel costs as the institution's responsibility and preferring to pay only for equipment rather than sign language interpreters (Howell 2005).

This exclusion has, according to Eleweke and Rodda (2002, 115–116), created an unfavourable situation whereupon gaining admission these students 'are [left] on their own as they receive no special support to help them on their courses'. The rationale behind selective inclusion is the marketised framing of these students as difficult to accommodate as a result of needing 'too much' specialist assistance (Singal 2005, 6). Under this selective inclusion approach, students who are deaf are being served poorly, especially in countries like South Africa as NSFAS guidelines 'do not fund human support (scribes, sign-language interpreters and note takers, etc.)' (FOTIM 2011, 137). The same holds true for some Indian HEIs, such as Adarsh College in Chamarajpet, Bengaluru University and Delhi University, where the absence of sign language interpreters has forced some students who are deaf to pay out of pocket themselves for lessons with private interpreters at exorbitant rates (Krishnan 2012). In contrast, Australia stands out among the sampled countries as having been able to maintain good practices despite the challenges of budgetary constraints as it has responded positively to the increasing enrolment levels of deaf and hard of hearing in its HEIs by employing more and more interpreters (Knuckey et al. 2001; see also OECD Higher Education Programme IMHE 2014).

Following Howell, achieving genuine inclusive education for students with disabilities does not merely end with dismantling physical access barriers to HEIs, but most importantly through also putting in place mechanisms that can provide additional support to those students with disabilities who may require it (Howell 2005). However, evidence from our findings indicates that this has not come to reality, as most HEIs seem to focus mainly on achieving physical access for students with disabilities, thus leaving their academic success in jeopardy. As one Lancaster University DSA recipient who has autism commented:

> Just because I made it to university, does not mean I'll cope without support… Without DSA, the trivial things would become impossible for me—this also applies to many future disabled students, who are being ignored by the government (*Times Higher Education* 2015).

Students with disabilities must meet these additional costs in the course of coping with their disabilities, but often their incomes are lower than those of their non-disabled peers, which means that their dependence on state funding is higher, yet 'their opportunities have been diminished by the inadequate levels of financial aid, particularly grants' tailored for low-income students with disabilities (Wolanin and Steele 2004, ix–x). Funding cutbacks have meant that HEIs do not have enough funds available to meet all the needs of students with disabilities, resulting in students with disabilities themselves having to bear some of these costs out of pocket (Wolanin and Steele 2004). Similarly, 'the availability of state and institutional financial aid funds also is limited by either award limits or an excess of demand compared to funding' (Wolanin and Steele 2004, 60).

In both the Global North and the Global South, persons with disabilities are considered among the world's most vulnerable and least empowered groups (Khasnabis et al. 2010). This vulnerability of persons with disabilities has been attributed to high levels of poverty, which has resulted in this group's experiencing worse educational and labour market outcomes in comparison to their non-disabled peers (World Health Organisation (WHO) and World Bank 2011). The findings of this study show that the funding mechanisms of sampled countries still deny students with disabilities the capabilities to escape the poverty cycle by empowering themselves through acquiring tertiary education, which enhances their prospect of employment. This is particularly true of students with disabilities who are reliant on assistive technology, which is not covered in most of the sampled countries' funding mechanisms. This becomes a violation of inclusive education as provided in the UNCRPD, which imposes a responsibility on state parties to honour their responsibility to promoting and ensuring the availability and access to assistive technologies for students with disabilities if they are to participate fully in the classroom setting (United Nations 2006).

We critique the incentivisation of disability inclusion which is prevalent in the USA (Wolanin and Steele 2004), Canada (OECD Higher Education Programme IMHE 2014) and India (Jameel 2011) where funding to these countries has been allocated based on a number of students with disabilities enrolled annually. Although we acknowledge that in the wake of serious resource constraints HEIs will need funding, and resources should be made available to assist them in driving the disability agenda (FOTIM 2011), we argue that this approach will continue to benefit bigger HEIs in cities at the cost of smaller HEIs, especially those in under-resourced rural settings.

In India, for instance, given the abundance of assistive technology, the Indian Institute of Technology in Delhi has attracted many students with disabilities nationwide to come to study there (Joseph 2012), which means that this institution will always receive more funding than other Indian universities. Likewise, despite the fact that South Africa has leading universities which are internationally respected, because of the legacy of apartheid historically black universities continue to face severe financial, human, infrastructure and other resource constraints (Badat 2015). Unlike South African historically white institutions, some of these historically black universities still do not have Disability Units, which makes them unwelcoming to students with diverse disabilities. Seen from this perspective, we propose the need for the sampled countries to provide disability funding as per provided in their individual funding mechanisms as well as per the provisions of the UNCRPD, and particular focus should be on prioritising funding for smaller universities and universities of technology.

## Conclusion

The OECD has pointed to inadequate funding as one of the hindrances to the successful transition to tertiary education for students with disabilities (OECD 2011). Living with a disability entails expenses such as trips to doctors, therapists, counsellors and administrators (Wolanin and Steele 2004). While under all the sampled countries' funding models, students with disabilities are entitled to funding to offset the extra costs of living with a disability or a specific learning difficulty (OECD 2011), the current financial context sees institutions facing challenges with the provision of adequate funding to cover the extra costs which are incurred by students with disabilities in the course of pursuing their studies in HEIs.

While the increase in the number of students with disabilities enrolling in HEIs is, as we saw above, made possible by publicly funded grants, with declining public funding, there is a high possibility that numbers will once again fall. As access to grants and scholarships narrows, 'low-income students with disabilities [who] generally have a greater need for financial aid than their peers without disabilities' will be affected the most (Wolanin and Steele 2004, 63). Although the sample countries have widely embraced the practices of inclusive education as an ideal model for education (Maher 2009), these countries still have a long way to go with regard to financially supporting students with disabilities in a manner which widens their opportunities to access, participation, retention and success in HEIs. Because of funding challenges, it can be argued that inclusive education is being implemented narrowly in these countries in a way which perpetuates the exclusion and marginalisation of students with disabilities. As a result, the principle of inclusive education 'increasing participation and reducing exclusion, in a way that effectively responds to the diverse needs of all learners' (Kaur and Arora 2014, 59) is routinely violated in practice.

Because of inadequate funding, we see many countries resorting to selective inclusion or what Ndlovu and Walton (2016) have referred to as an impairment-based approach in supporting students with disabilities in which only particular categories of disability are accommodated by specific institutions. Impairment-based approaches have often seen HEIs prioritising providing RAs to certain categories of students with disabilities at the cost of others. For example, students who are deaf fare differently compared to other students because of the shortage of, and cost involved in providing, fluent sign language interpreters. This violates the overarching goal of inclusive education which is to ensure the participation of *all* students with disabilities in quality education to develop the full potential of these students (Kaur and Arora 2014). The result of prioritising some groups of students with disabilities at the cost of others is a form of selective inclusion determined by cost rather than meeting individual needs regardless of cost.

## Endnotes

1 Guided by the *United Nations Convention on the Rights of Persons with Disabilities* we approach 'disability' as "an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full participation in society on an equal basis with others" (United Nations 2006, 5).

2 Kraglund-Gauthier and colleagues have defined RAs as: 'involv[ing] minor changes that assist a student's functioning in the classroom by offering alternate ways of handling a task; for example, providing photocopied notes to a student with muscular dystrophy who has difficulty with writing' (Kraglund-Gauthier et al. 2014, 2).
"Common forms of accommodations in the postsecondary context would, for example, include provisions such as 'extended time on exams, alternative exam formats, and assistance with note-taking, study skills, and learning strategies" (Lombardi et al. 2011, 250).

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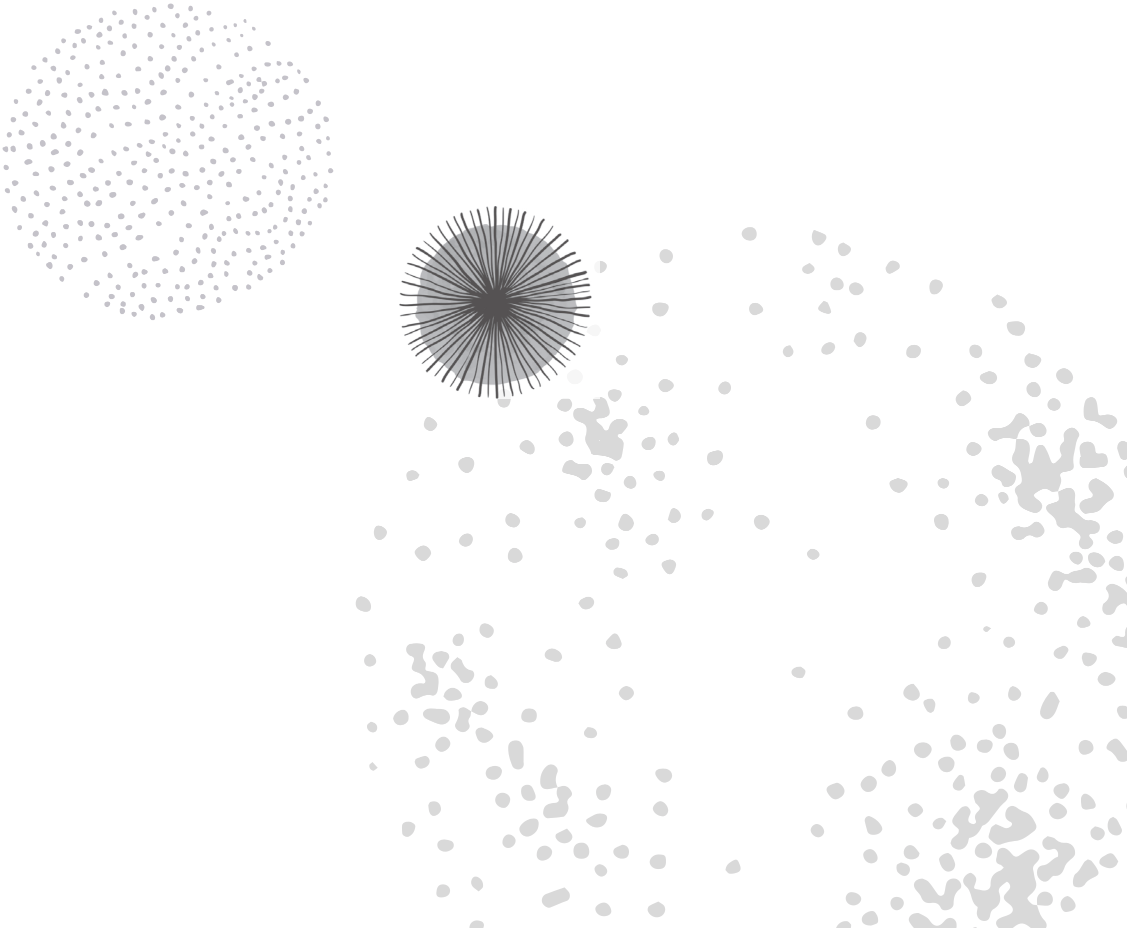

# CHAPTER 5

## ‘NOTHING ABOUT US WITHOUT US’: CREATING SPACES FOR DIRECT ENGAGEMENT BETWEEN DISABLED AND NON-DISABLED UNIVERSITY COMMUNITIES

Deirdre van Jaarsveldt, Charity Ndeya-Ndereya, Martie Miranda
and Louzanne Coetzee

### Abstract

In this chapter, Deirdre van Jaarsveldt and colleagues explore how the concept of direct engagement between students with disabilities and the non-disabled university community in the form of different platforms of dialogue can create an enabling environment for changing attitudinal prejudices against students with disabilities, resulting in the promotion of inclusive education on South African campuses. The chapter draws on data from various participants, including students with disabilities’ experiences of e-learning needs, discussions between students with disabilities and their non-disabled peers on how they experience residence life, and lecturers’ experiences of how they support students with disabilities in the teaching and learning process. The findings of the study reveal that significant barriers hindering inclusivity for students with disabilities stem from a lack of effective communication and liaison between relevant stakeholders on campus, lecturers who constantly refer students with disabilities to Disability Units rather than seeing themselves as responsible for effectively teaching all their students, and a one-size-fits-all approach to addressing the learning needs of students with disabilities. The study also identifies some best practices which includes the positive role played by students with disabilities who are using their self-advocacy skills to sensitise the non-disabled community—especially university management—about disability issues. The

chapter highlights the need for universities to promote contact between students with disabilities and the non-disabled community through various platforms which promote dialogue to enhance the non-disabled community's understanding of disability issues as well as reducing prejudices against students with disabilities. Recommendations for platforms where direct engagement between students with disabilities and the non-disabled university community can take place include, for example, disability awareness raising workshops, and *Disability Indaba* led by students with disabilities themselves.

## Introduction

Direct engagement between the disabled and non-disabled university communities is an essential part of inclusive education. In ensuring equal education opportunities and a sense of belonging for all, there needs to be respectful mutuality amongst everyone involved (Swart and Greyling 2011). The participation of students themselves is crucial in understanding the challenging process of establishing an inclusive university environment for students with disabilities (Moswela and Mukhopadhyay 2011). In this chapter, we shall explore the role of students with disabilities sharing their experiences in promoting inclusivity for them on a university campus.

Through our lived experiences, research and work with students with disabilities at our institution we have developed a deep understanding of the complexity of disability as a phenomenon. In conceptualising disability, and specifically for the purposes of constructing a theoretical foundation for inclusive education, we therefore support an integrated model of disability, enriched by a variety of theories. One of the theoretical models most often applied in support of inclusivity is the social model of disability (Gable 2014; Moriña et al. 2014). In attempting to provide a truly inclusive environment, however, we have learnt that we cannot approach disability merely as a social construct, another form of diversity. We need to consider its complexity, view disability within context and acknowledge the presence of an impairment that together with societal barriers are impacting upon the person's life (Dunn 2009; Gable 2014; Shakespeare 2006).

Social inclusion alone cannot enable academic success for students with disabilities. When, for example, someone is experiencing physical pain, difficulty in breathing or fatigue they cannot function at their best. Students with sensory disabilities, for example, those who are blind, cannot see visual cues that provide additional information, whilst students who are deaf cannot hear the tone of what is being conveyed. Beyond learning difficulties often experienced by persons with autism spectrum disorder, these students may have severe difficulties in relating to people, and group participation or assessment will consequently present many challenges (APA 2013; Shakespeare 2006). These are only a handful of simple examples to illustrate the influence of context and to motivate why we agree with the idea that a one-size-fits-all approach to support students with disabilities will never suffice (Rose 2013). Furthermore, Tom Shakespeare (2006, 60) highlights that 'impairment is scalar and multi-dimensional, and differences in impairment contribute to the level of social disadvantage which individuals face'. Even in removing social barriers and making learning more accessible, students with disabilities are still having to navigate a range of incapacitating challenges (Bury 1997; Shakespeare 2006). The extent and severity of these challenges depend upon the particular difficulties confronting them as individuals.

If we, as university community members, are to be proactive in our support of students with disabilities, we need to ensure that the non-disabled community develops a thorough understanding of the complexities students with disabilities have to deal with in their day-to-day lives. As Dunn (2009) rightly indicates, narratives can be powerful teaching tools and people learn best from the persons with disabilities themselves. In our experience, there is no substitute for hearing the voices of those directly affected by an issue. Such deep engagement, where perspectives and experiences are freely exchanged, creates a fertile environment for transformative learning (Van Jaarsveldt 2013; Wang and Geale 2015). During such an exchange an opportunity is created for the participants to develop a deeper understanding of an issue, to reflect critically on their assumptions, and to examine alternative perspectives (Brockbank and McGill 2012; Kroth and Cranton 2014). This insight could have a life-changing effect, because once a person's perspective has changed, their behaviour changes too (Mezirow 2012).

We consequently regard deep engagement between the two communities to be a precursor for non-disabled members to respond constructively and take effective action towards creating genuinely inclusive universities. It is our belief that encounters should be created where students with disabilities can share their experiences, voice their concerns and express their needs. The non-disabled community also needs a platform where they can question, gain factual knowledge, overcome their fears and misperceptions, and become comfortable in their interaction with people with disabilities (Van Jaarsveldt and Ndeya-Ndereya 2015; Wang and Geale, 2015).

## Background

The authors of this chapter connected when Charity and Deirdre conducted an e-learning needs analysis of students with disabilities at the University of the Free State (UFS) between 2012 and 2013. The study involved the participation of lecturers and students with various forms of disability, and we liaised with the Centre for Universal Access and Disability Support (CUADS) throughout the process. Data were collected by means of a survey, as well as in-depth individual and nominal group interviews. The findings revealed significant barriers to communication and liaison between various role-players on campus (Ndeya-Ndereya and Van Jaarsveldt 2013). There was therefore a definite disconnectedness that impacted negatively on inclusivity, to say the least.

We also noticed that some of the participating lecturers distanced themselves from the students and transferred their responsibilities to the CUADS. This stimulated a further exploration to assist us to better understand the reasons for lecturers not being inclusive in their educational practices. The main issues that emerged were a lack of knowledge and skill, a lack of anticipation and psychological barriers, such as fears, concerns, feelings of vulnerability or inadequacy, and embarrassment (Van Jaarsveldt and Ndeya-Ndereya 2015). Meaningful contact between role-players was necessary to promote a more accurate understanding of the experience of disability to reduce prejudice, and thus to advance inclusive education (Dunn 2009). We realised that there was a burning need for the participation of students with disabilities in our professional development and inclusivity work.

To create spaces for direct engagement we subsequently started incorporating deep encounters in our respective endeavours. These efforts will be explored from the perspectives of: Martie, the Head of CUADS; Louzanne, a student representative; as well as Charity and Deirdre, researchers from the Centre for Teaching and Learning (CTL), who have also engaged in student and staff development with regard to disability support. The benefits and barriers relating to direct engagement between the disabled and non-disabled university communities will be discussed by means of a collaborative reflexive approach to the work done in this regard at the UFS.

## Methodology

Since completing the e-learning needs analysis of students with disabilities, we have continued engaging collaboratively in action learning and action research. Participatory Action Learning and Action Research (PALAR) characteristically involves cycles of collaborative identification of needs; deciding on the best course of action; implementing the action; evaluating it; and deciding what further action to take, based on participants' critical reflection upon the process (Zuber-Skerritt et al. 2015). All our endeavours have continuously been developing through this collaborative work.

Within disability research there is a call for inclusive approaches that incorporate methodological plurality and contextual understanding, whereby the voices of 'insiders' are emphasised throughout the research process (De Bruin 2015; Dunn 2009). In this chapter, we share our narratives about incorporating student experiences in promoting inclusivity for them on a university campus. Substantiating evidence is presented with the informed consent of participants. In accordance with PALAR, values-based ethics applied in this research where we held one another accountable to the 7 C's, i.e. collaboration, critical reflection, communication, competence, coaching, compromise, and commitment (Zuber-Skerritt *et al.* 2015; Zuber-Skerritt 2018). We pursued authenticity by striving to present honest and truthful descriptions and explanations that could enhance knowledge, deepen understanding, and facilitate transformation. Authenticity includes prolonged engagement; data source triangulation; consideration of multiple perspectives; member checking; thick and contextual descriptions; reflexivity; a dialectic approach; and reporting of discrepancies (Botma et al. 2010; Zuber-Skerritt et al. 2015).

In agreement with Andrews et al. (2013), we intend taking an experience-centred approach to the narrative that focuses on internal representations of phenomena. We acknowledge that these accounts are context bound and could evolve over time and circumstances. We intend starting our exploration by presenting our separate narratives, followed by a content analysis alongside a critical appraisal of emerging ideas in literature (Bold 2012).

## Martie

The CUADS plays a crucial coordinating and facilitating role at the UFS to ensure that support for the inclusion of students with disabilities is provided in the physical, emotional, social, academic and support environments of the university. We attempt to address barriers that students with disabilities experience in their different environments by advocating the students' views, opinions and experiences as a strategic responsibility. This includes overcoming prejudices and discrimination, such as attitudes, stereotyping, assumptions and inflexible or unfair systems that create a disabling world. There is a dire need for increased awareness and responsiveness towards students with disabilities. Statements such as: 'how can you let my child share a room with a disabled student and have the responsibility to take care of her (E1)' are the types of general misperceptions that the CUADS needs to address on a daily basis. Consequently, during 2016, the CUADS embarked on looking for opportunities for students with disabilities to share their narratives and experiences of student life with other students and stakeholders at the UFS. The purpose of these encounters was to address assumptions and increase awareness about disability. The intention was to initiate discussions and dialogues about the inclusion of students with disabilities in the previously mentioned environments.

We requested informal discussions within residences through the Residence Committee Representative for Diversity. A team of students with disabilities representative of all the disability categories were invited to engage in discussions with non-disabled students residing in the particular residences. Students from both communities shared their experiences of being students on campus and questions were answered. One of the students with disabilities expressed appreciation for being asked questions such as:

> Would I like them to assist me in anyway when they meet me on the way? Can they talk to me and ask any questions based on my disability? How am I studying, writing my tests and exams, etc.? How did it happen that I became disabled? (B1).

The interactions assisted in creating a curiosity and enhancing understanding, according to the same student with disabilities:

> The reaction I received from students was really a positive one, and I was impressed. They were willing to listen attentively. They showed a lot of interest. Most importantly, they asked questions on what they were not certain about (B1).

The student felt empowered by the opportunity to engage and found her presumptions about non-disabled students confirmed:

> My participation in the dialogues had a positive impact on me, because it is something that I have been longing to do, which is interacting with other students about my experiences. It also confirmed my suspicion that students are interested in knowing more about students living with disabilities and to interact with them, make friends with them and to mingle with them. They don't want to see us as strangers, or even as weird, walking around campus. They are also keen to learn more about the disability culture CUADS (B1).

During these discussions, misperceptions about the non-disabled community being disinterested and detached were overcome. The playing field was levelled through comfortable interaction.

Another form of dialogue was arranged during Disability Rights Awareness Month regarding inaccessibility experienced on campus. The dialogue included the University Estates Department as stakeholder and was facilitated by a representative of the Institute for Reconciliation and Social Justice. Students with physical disabilities shared specific examples of inaccessibility they often experienced. One of the students demonstrated that the only way for him to be able to see an ATM screen was to push himself up on his wheelchair's armrest. The Institute representative presented photos of specific distressing situations, for example, where a student who is blind, making use of a guide dog, got lost when construction work obstructed their regular walking route. After the meeting, the student participants were requested to provide feedback via email regarding their experience of the dialogue. One of the students expressed an appreciation for not being pitied and for being granted an equal opportunity to participate. He confirmed the need for continued engagement in order to eliminate preconceived ideas about disability. In response to the dialogue report, which was distributed to the stakeholders, a staff member from the University Estates Department shared having gained insight: 'I now understand their frustrations" (S1). The exchange brought mutual satisfaction for all participants.

During the registration period for first-year students in 2017, an urgent situation in a residence necessitated an emergency meeting. An information session was held between a CUADS representative, the Residence Head and the Residence Committee who were expecting a student with disabilities to move into their residence. Not having had previous experience in this regard, they were driven by fear, uncertainty, and ignorance about providing accommodation for a student with disabilities. A student representative was not present to clarify the possible needs of new students with disabilities and the following concerns were raised:

> How are we going to support her? Will she be safe on the stairs? How do we make her feel welcome like the other first years? (S2).

A better understanding developed after more information was shared about the possible needs of the students with disabilities, together with the support that will be provided by the CUADS. The Residence Head reported:

> The reaction was emotional after the possible needs of the student were shared, because our responsibility in making sure that the student shares the same experience as any other first year became somewhat serious (S3).

This response alerted the CUADS to the fact that continued liaison and support is necessary. We realised that collaboration with various stakeholders at an institution is vital. Moreover, the involvement of students with disabilities is indispensable in negotiating integration, inclusion and participation at all levels and phases of their student life. Ultimately, university life should be barrier free to the extent that students with disabilities feel that they count as people and are not viewed merely as a burden. Through the sharing of their lived experiences and by embracing opportunities of discomfort and uncertainty, deep learning experiences are created for all.

## Louzanne

The higher education landscape has always been one filled with challenges when it comes to disability. Although more students with disabilities are now pursuing higher education, much must still be done to make the environment accessible and easy for them to live in (Swart and Greyling 2011). As we have already indicated, the experiences of students with disabilities are all different and situational depending on the type of disability, the person involved, the types of barriers, and so forth. Barriers may include physical, academic, social, recreational and others. These barriers are certain to limit the participation of these students in the higher education landscape (Moswela and Mukhopadhyay 2011).

Having experienced many of these barriers myself as a blind student, I have found that disability support is vital for the success of any student pursuing higher education. As far as my experience goes, support is mostly provided on the academic front with some additional support for recreational activities, such as the performing arts and sport, if possible. However, for disability support to be effective at university level, circumstances of individual students need to be taken into account. Therefore, communication from the student about their needs and challenges is vital. Without this information provided by the student, holistic support is virtually impossible.

A lack of communication by students with disabilities often contributes to misunderstandings and misgivings about these students by lecturers, peers, and support staff at higher education institutions. This could cause unwillingness to assist, uncertainty, and, in certain cases, no relationship to form at all. It is vital that students make use of their experience, knowledge about their disability, and knowledge about fellow human beings to create their own productive and accessible environments. Students with disabilities need to realise that they cannot only rely on support services at universities to create better environments, but that they have to contribute towards making their lives at tertiary education institutions more accessible, productive, and successful.

I served on the Student Representative Council (SRC) between 2014 and 2015 at the UFS and had the opportunity to experience the struggles of my fellow students with disabilities first-hand. During this period, we tried to get an association for students with disabilities off the ground (Additionally Challenged Student Association). It was thought that this association could provide a voice for students with disabilities, ensure adequate representation within CUADS, and organise activities that would bring students with disabilities together. It was then that I saw the lack in communication from the students’ side. Here I realised that part of the problem at the UFS was that students were not speaking up or taking initiative to make their own lives better. The lack of participation by students with disabilities themselves saddened and shocked me. At the end of 2015, our association was abandoned due to the lack of interest and participation by students. I learnt that for things to improve, students with disabilities themselves would have to start participating and communicating about themselves in order to educate those around them about disability.

I do understand, however, that this is not necessarily as easy as I make it sound, because students have different situations, needs, and personalities, with the barriers students with disabilities face often being situational (Duquette 2000; Shakespeare 2006). Often something another student might find to be a barrier or stumbling block is not necessarily a barrier or stumbling block for me, and vice versa. This complicates the situations and barriers that students with disabilities face when they enter the higher education landscape.

Complications like these made me realise that other projects and initiatives need to be undertaken from the students' side to try to connect with lecturers and support staff on a personal level. Here, the students could share experiences of exclusion with them and make them understand how students with disabilities experience higher education. However, this is not the only aspect I wanted initiatives and projects to address: I also wanted to try to give staff at the university useful knowledge they could apply in and out of the classroom to connect with students with disabilities. I therefore launched a *Disability Indaba*—focusing more on academics – as well as a project called 'The Challenge', which focused on physical access and how students with disabilities experience day-to-day life on campus.

The first project, initiated by my portfolio on the SRC (Accessibility and Student Support), was the *Disability Indaba*. This initiative focused on supporting lecturers to work together with students with disabilities in the classroom. The event comprised of presentations by different speakers, for example, persons who had experience in lecturing students with disabilities or working with people with disabilities, as well as students themselves. The programme also included question-and-answer sessions and small group discussions. The event focused on the shared experiences of students with disabilities in the classroom, as well as the experiences of lecturers who had previously worked extensively with students with disabilities. Representatives from all faculties were present and the dialogue from the different role-players was free and forthcoming. During this event it became clear that narratives of students with disabilities and the experiences they share with lecturers are more powerful than just simply conveying information.

Written feedback from the *indaba* was positive, with many participants clearly showing a preference for narrative instead of academic information regarding the topic of disability. From the feedback it was also evident that many participants felt that there is a great need for similar events on campus and that they would enjoy a follow-up event. Participants were also comfortable in an environment where dialogue was forthcoming. They felt that when other participants made themselves vulnerable by sharing personal experiences it made it easier for everyone else to open up and communicate what their experiences had been. The event taught all role-players, both disabled and non-disabled, something about each other. I believe that more opportunities like this need to be created for us to learn to understand each other better.

The second event I held was called 'The Challenge'. In this event, members of the university rectorate were placed in the position of the disabled for one day. They continued with their scheduled activities while either being in a wheelchair, blind folded or restricted in their communication by not being permitted to talk. One of the members, for example, had to address a large gathering while being blindfolded. Once again, exposing the participants to a lived experience was more powerful than simply relaying information, suggestions, or complaints about physical access on campus to rectorate. They experienced difficulties with access exactly like the students with disabilities on our campus do on a daily basis. The members of the rectorate had difficulty finding accessible bathrooms, struggled to navigate ramps, couldn't reach doorknobs, had trouble working the ATMs on campus and found counters too high in the administration building when they wanted to speak to the staff manning said desks. Deep engagement proved to be an effective transformative learning tool, because the participants developed a thorough understanding of the issues at hand.

Another project I participated in during my term on the SRC was an initiative coordinated by my colleague Deirdre who presented a series of difficult dialogues where she got staff members of different divisions together to talk about difficult issues. This included issues that staff members were afraid to tackle head on with students with disabilities themselves. I, for example, participated in a dialogue with residence heads where we talked about access in residences and the difficulty of students with disabilities integrating in residences. I got to share personal anecdotes of residence life and I felt that sharing my real-life experiences made a big difference in the staff members' understanding of how students with disabilities experience residence life at our university. I shared with residence heads how difficult I found certain induction practices, such as hazing, because one of the main requirements would often be that one should be able to see (We had to, for example, run about campus at night to chase male students back to their residences). I also explained the difficulty I had in finding residence placement after I got my guide dog. I believe the fact that my colleague also used the personal narratives of students instead of academic information made a great impact on how staff members she worked with view students with disabilities.

After five years of personal experience, I have realised that the manner in which you address a challenging situation as a student will affect the impact it has on those you are working with. I learnt that I need to try and gauge what type of reaction will make the greatest impact on those around me in a particular situation. An example of this is in my third year, when I withdrew from engaging with a lecturer completely and deregistered from the module instead of staying in his class and challenging his mind-set. During this year I had a compulsory computer marketing module. The first day when I entered the classroom my lecturer came up to me and stated that he had no idea how I would be able to finish this module and that we would have to look at alternative options for me to complete my course. I found him intimidating, so I immediately made a plan to drop the module and take something in its place. This sounds uncomplicated and easy now, but the implications of this were vast. Firstly, I had to get permission from the dean of my faculty to replace the module and take something else. After this, written permission had to be given from various members of my faculty for me to take a replacement module. Dropping the module was a lengthy process and created a lot of administration work for many people involved. In retrospect, perhaps I should have stayed in his class and showed him that with hard work and determination it would have been possible for me to complete his module.

Another example of where the manner in which one deals with a situation will make an impact on the outcome was when I first got my previously mentioned guide dog Oakley. As service animals were a very new idea for my university at that stage, I struggled with the housing and residence department who didn't want me to live in my residence with my dog. However, this time I stuck to my guns and insisted (with the support of the CUADS) that it would be easier for me to stay in my residence. I was met with a lot of fear and uncertainty about my furry friend, but managed to solve the problem and clarify the misgivings amongst the ladies in my residence. Simple communication and explanations about what the dog is for and how my routine with her works sufficed. The Department of Housing and Residence Affairs grudgingly gave it a try and it was smooth sailing with Oakley in the residence with me. Nowadays it's much easier for students with service animals to enter and stay in residences. In this situation I realised that communication and my attitude would determine a large part of the outcome of the situation.

The last experience I will share here is regarding disability sport at my university. Five years ago, sport for the disabled was a strange, far-away concept that never had to be dealt with before. I found the sporting department to be hesitant to familiarise themselves with the concept, and unwilling to coach me (up until today I am coached by an external athletic coach). This is one situation where no amount of positive attitude has made any changes thus far. The experiences of disabled athletes are not a priority for the university's sporting department, and, effectively, there is very little communication and dialogue regarding sport at this institution. For example, I had to manage my own academic calendar, without any support, whenever I was off campus with sporting events. I had to make my own arrangements for the moving of examinations, such as with my participation in IPC (International Paralympic Committee) World Championships and the Paralympic Games.

The medical model of disability seems to inform their approach towards students with disabilities as needing special services and separate facilities, thus placing disability within a special education paradigm (Gable 2014). This makes it difficult to drive inclusive (disabled) sports at my university, because, to some extent, the Department of Sport is blocking the transformation agenda. They are also unwilling to be educated in this regard, which makes it even more difficult. To be honest, even at the time of writing this I do not know how we are going to solve this problem. I now participate on my own, am coached on my own, and only belong to the university club for an athletic licence. Although I have achieved substantial success in the disability sporting world, and am currently the world record holder for the 5000m for totally blind female athletes, I still feel disempowered in this context. I have never encountered such a difficult situation where I have experienced a total rejection of disability.

Apart from this case, however, my experience at university has been that people are usually willing to change their mind-set and be educated regarding disability. By use of a communicative, open approach, I have nearly always succeeded in bridging the gap between myself and a non-disabled peer. I have found that providing people with real experiences and tangible evidence and having a positive attitude go a long way. I learnt that as soon as students have made themselves vulnerable and put their shortcomings, struggles and personalities forward, lecturers and other support staff for students are more willing to negotiate, change their mind-set, and meet the student halfway. This proactive approach promotes independence, inclusion, and a willingness to compromise. In this manner, most difficult situations, stumbling blocks, and obstacles can be removed from the paths of students with disabilities (literally and figuratively) at higher education institutions.

## Charity and Deirdre

Following the e-learning needs analysis of students with disabilities, we found our role evolving from that of researchers to agents of inclusivity for students with disabilities. Having discovered the various barriers experienced by the students, as well as non-disabled persons, we consequently started creating opportunity for engagement amongst various members of the university community. We made valuable discoveries in the process.

The research report was distributed to all the participants of the study, as well as all the stakeholders on campus, after which we called a stakeholders' meeting to discuss the recommendations. The meeting was well attended and there was unanimity about the need for effective liaison. There was also full agreement that the implementation of Universal Design for Learning (UDL) could increase student success for all, and that this approach should be integrated into teaching and learning on our campus. Unfortunately, the attendance of follow-up meetings started to dwindle, and it became increasingly difficult to maintain the momentum displayed during the first meeting. This was especially difficult for us, as we were not in a position of authority to ensure effective progression.

We started taking a bottom-up approach by incorporating inclusivity for students with disabilities in our day-to-day work at the CTL. When promoting excellence in teaching and learning, or when presenting tutor and staff development initiatives, we started including students with disabilities. The first initiative involved a panel discussion that formed part of the Teaching and Learning Excellence Day held on campus in 2013. Members of the disabled and non-disabled communities were in attendance and the panel consisted of a lecturer, a researcher, a blind student, and a representative of CUADS. The event was well received, and we received positive written feedback.

When a national teaching and learning conference was hosted by the UFS during 2014, we took the opportunity to do something similar that could extend the work to a national platform. Since the event was held on campus, it was possible for our students with disabilities to attend. We presented a pre-conference workshop that included a representative panel, as before, but added small group discussions. Each of the small groups explored the learning needs of students with a specific form of disability that falls into the category of visual, hearing, mobility impairment and Specific Learning Difficulties. Our students sparkled as they participated actively in sharing their experiences with the group members. Anonymous feedback was obtained by means of the Critical Incident Questionnaire (CIQ), a five-item open-ended feedback sheet that was developed by Brookfield and Preskill (2005). The participants reported being engaged throughout the session and the majority found the group discussions to be the most engaging part of the workshop. They indicated that what they found most helpful and affirming was the contributions from the students. Some of the comments from different participants in this regard were as follows:

> Engaging with the students in-depth—disabled students' experiences (HPWS4).
>
> Information from students and how everyone came up with solutions, especially on communication (HPWS5).

> I felt the views of the disabled students most informative (HPWS6).
>
> When people shared their experiences that was really helpful and eye opening (HPWS7).
>
> When the disabled students shared with us their daily challenges and experiences (HPWS9).
>
> When students openly talked about their experiences—what they prefer and what they don't prefer (HPWS10).

These statements confirm our belief that deep engagement provides fertile learning ground.

The participants reportedly learnt most from the student experiences. To the question of *what surprised them most*, this was reaffirmed. Amongst a variety of individual responses, a few participants referred to how informative they had found the workshop. One participant exclaimed, '[a] fantastic and highly informative workshop' (HPWS4). Another participant provided deeply reflective feedback by indicating being surprised about their emotional response to the first encounter with a student with a disability, as follows: 'how scared and a bit uncomfortable I was when I first started talking to the disabled student' (HPWS9). The same participant indicated on the CIQ that the discussion session was the most engaging part of the workshop and that the student sharing daily challenges and experiences was most helpful and affirming. To an additional question we had posed about what could render the environment more conducive to discussion, this participant expressed a need for deeper engagement: 'To talk about our feelings with disability' (HPWS9). This provides evidence that deep engagement does present opportunity for participants to overcome fears and to be critically self-reflective about their internal barriers to disability and inclusivity. It also confirms that there is a need for continued engagement on progressively deeper levels.

The success of the pre-conference workshop inspired us to include disability in the training workshops we were presenting at the CTL. As coordinator of the Difficult Dialogues Project, Deirdre started incorporating the theme of disability in this work. Difficult Dialogues is an international initiative that promotes respectful, transformative dialogue on controversial topics and complex social issues within universities. Extensive support and development work had already been done at the UFS by means of Difficult Dialogues workshops and interactive sessions for staff and students. Participants had previously been engaged in explorations of inclusive learning environments for various disadvantaged groups. Now students with disabilities started joining our inclusivity sessions and the theme of non-disabled privilege was included in the sessions relating to privilege. Louzanne and the head of CUADS at the time facilitated numerous discussions on disability. A wide variety of participants—from residence heads, academic and support staff, teaching assistants, as well as tutors and students—were reached through this initiative. Written feedback from each workshop, obtained through short reflections and the CIQ, confirmed and supported the previous findings. The voices of those directly affected by an issue were found to be a most effective teaching and learning tool.

Charity invited students with disabilities to the UDL workshops for newly-appointed tutors, where they were engaged as panellists or joined discussions on their expectations and needs during tutorial sessions. The analysis of tutor evaluations from each of the four workshops conducted during 2015 and 2016 revealed that they appreciated and valued the physical encounters and interaction with the students with disabilities. Again, previous findings were reiterated. The tutors reported having gained an appreciation for diversity; insight into students with disabilities' needs and expectations regarding tutorial sessions as well as a better understanding of the different disabilities, including some they had not been aware of. Having heard how the students struggle to learn and cope at university, they also learnt how to respond to students with various forms of disability. One tutor was surprised to find 'students educating tutors' (C8), thus highlighting the reciprocity of learning that took place. Similar sentiments in support of direct engagement recurred in every training session.

Some tutors reflected on their tutorial practices and started self-evaluation. This was evidenced by the following statements:

> Students with disabilities sharing their thoughts and learning experiences… showed me how I'm doing and what I'm doing wrong against them (T12).
>
> Now I know how to conduct myself around students with disabilities (C13).
>
> Learning about the different ways in which all students learn and that I need to adapt my tutorial style accordingly (C15).

One tutor summed up the workshop encounter with students with disabilities by stating that 'Having disabled students engaging with tutors gives tutors an opportunity to clear up any misunderstandings/misconceptions about disabled students' (C14). The statement indicates that the purpose of overcoming misperceptions through direct engagement between the two communities was accomplished. An exchange of perspectives with an opportunity to clarify and change misperceptions forms the basis of transformative learning (Mezirow 2012).

The tutors' encounters with students with disabilities were not always pleasant, especially at the beginning. As was the case at the pre-conference workshop, occasional feedback statements referred to emotional experiences, for instance: 'At first I was a bit nervous, but all the tips I got made me feel at ease' (T1). Another tutor stated that the workshop facilitator should have warned the tutors that 'It might become emotional for some people and maybe provide some tissues if someone cries' (T6). This statement refers to an incident where two students with cerebral palsy shared their classroom experiences with the group. The participants were deeply moved.

At the end of each session, the participants expressed the need for more interaction with students with disabilities because they wanted to continue expanding their knowledge base and repertoire of experience. Once the ice had been broken, the need for closer encounters emerged time and time again. As time progressed, the students with disabilities who participated in these efforts displayed more confidence in voicing their needs. Some volunteered to participate again in future and others even expressed the desire to become tutors themselves. We take this as evidence that they have been empowered in the process.

## Discussion

Our work in creating spaces for direct engagement between the disabled and non-disabled communities on campus presented many challenges and learning opportunities. During a thematic analysis of our narratives, five main themes emerged, namely: effective communication; identity development; self-advocacy; academic explanation versus sharing of experiences; taking a bottom-up approach.

- Effective communication

Deep engagement between the two communities was characterised by effective communication. In particular, where there were equal participation and a respectful exchange of ideas, perspectives and experiences, participants reported having developed a deeper understanding of the issues surrounding disability and having engaged in critical self-reflection (Wang and Geale 2015). Reciprocal learning took place, where tutors admitted having learnt from students with disabilities and where students with disabilities found their misperceptions about non-disabled people being corrected.

Often, simple explanations sufficed when students approached staff or fellow students to make their requests. We found that someone needed to start the conversation and when students initiated dialogue it broke the ice for those who may have had difficulty knowing how to approach people with disabilities and interact with them. Where communication was shut down, however, there was little movement in opening participation for students with disabilities. Here, Louzanne's experience with her attempts to participate in sport on campus and her decision to drop a compulsory module serve as examples.

- Identity development

In asking students to share their learning needs with various audiences, they were in essence asked to make themselves vulnerable. They had to come to terms with their shortcomings and express it in public to enable non-disabled community members to develop an understanding of their roles and responsibilities in promoting inclusivity. This could be deemed as unreasonable towards students with disabilities. However, this proved to be an effective tool to bridge the gap between the disabled and non-disabled communities. The sharing of their experiences opened the floor for meaningful discussions where others could follow suit. They were granted an opportunity to master skills such as communication, assertiveness, problem-solving, conflict resolution and decision making that Swart and Greyling (2011) deem essential for the development of autonomy.

Furthermore, students reported feeling empowered after having had the opportunity to share their experiences and displayed increasing confidence and motivation to participate in future engagement sessions. Similarly, Helskog (2014: 81) found that students experience personal development when they engage in transformative dialogue:

> Many students claimed they had become socially more confident and courageous due to the project, implying that they to a greater extent dared to take contact and

> sustain contact with more people. This implied becoming free of inner (or outer) structures that hindered the students in living a healthy social life.

Making themselves vulnerable and expressing their needs reportedly contributes to their identity development, gives them a voice and provides access for others to enter their world.

- Self-advocacy

Having become more self-assertive and pro-active in their approach has also been fruitful in bringing about positive change to meet their needs. Participants often reported how much they had learnt from the students themselves. In accordance with Vaccaro, Daly-Cano and Newman (2015), we have found that the students with disabilities experience a sense of mastery when they have had an opportunity to engage with non-disabled persons and to self-advocate. Self-advocacy is an essential component of establishing a sense of belonging and, consequently, promoting academic success for students with disabilities (Vaccaro et al. 2015). Taking a proactive approach by engaging with one another directly is key for both the disabled and non-disabled communities. Students should be involved actively in improving their own lives at tertiary education level. Students with disabilities need to make the most of their opportunities to engage and should know that there are disadvantages to not having the confidence to approach people, such as, for example, their lecturers.

- Academic explanation vs sharing of experiences

Where we initially thought that an academic explanation would be the preferred route to enable transformation at an academic institution, this cognitive work had little effect in comparison. We found the sharing of experiences to be more effective. Within the domain of transformative learning, Kroth and Cranton (2014: 138) also found students’ stories to be more meaningful:

> We find, in our teaching, that when we invite students to ‘tell a story’ about their experiences or to relate ‘their story’ to a theoretical concept, the learning is much more meaningful than if the discussion stays on an academic and detached level.

In addition to narratives, we found immersive experiences, where participants were placed in the position of someone with a disability, to be a powerful tool in deepening their empathy and understanding for students with disabilities and their daily challenges. Also, incidents where participants had emotional experiences proved to trigger deep learning. In their feedback, these participants requested continued and deeper future engagement. Affective insight seems to provide momentum for transformative learning.

- Taking a bottom-up approach

The role of non-disabled staff members was a double one: they were advocates for the disabled community and intermediaries to initiate contact, provide information and offer support to the non-disabled community. We learnt that we could not rely on management structures to take the initiative; we needed to be agents of inclusivity in our everyday endeavours. We were the people who had gained a deeper understanding; who had developed a deep passion for the people and the work. We had to use that positive energy as momentum to drive inclusivity initiatives within our reach and pass them on to others within the non-disabled community.

## Conclusion

In diversity and inclusivity work, we have often encountered disruptive approaches to addressing issues, and our work has occasionally been viewed as attempts at softening difficult issues. Yet our experience has taught us to value respectful engagement. We have found that hearing the students' experiences first-hand not only increased insight, but deepened empathy and served as a catalyst for transforming paradigms and practices. Once hearts had been touched by students' narratives, people were motivated to take action. We can echo Bold (2012: 87) in saying that narrative 'is central to human experience and existence to share the nature and order of events at particular times in history. It helps to define self and personal identity'. We have found that affective insight facilitates action. Moreover, while disclosure of their experiences placed students in a vulnerable position, it contributed towards their identity development.

A one-size-fits-all approach is insufficient in meeting the needs of students with disabilities, and it also does not suffice in addressing issues of inclusivity. There were situations in which direct engagement did not have the desired outcome, especially when students were met with opposition from staff members. Whilst self-advocacy is important and effective, there needs to be a concerted effort, especially in cases where there is resistance to inclusion. It is essential for non-disabled members to work alongside them to advocate for them, to intermediate between the two communities, and to offer all-round support. We have found that through working closely together, we have not only strengthened the inclusivity efforts for students with disabilities, but have become sources of wisdom and support for one another in times of challenge and disappointment. Through the discussions we have had we have gained deeper insight and have been able to come up with more productive ways of dealing with difficult issues.

In future, we need to explore the barriers to inclusion of students with disabilities in recreational activities such as sports. An exploration of the distancing behaviour by lecturers helped us to develop a better understanding of their context and experiences. This in turn guided our staff development approach and actions. Slowly, but surely, we have experienced a warming up and comfort developing, in the interaction between the disabled and non-disabled communities. Similarly, we believe that a contextual exploration of the dynamics involved in sports and other recreational activities will inform agents of inclusivity on how to break down barriers and promote respectful mutuality.

Future engagement opportunities and research should extend to staff with disabilities. It might also be worthwhile focusing on the affective aspects of transformative dialogue, such as empathy development and the effects of vulnerability. Studies on a larger scale in other contexts could present a more complete picture of inclusivity efforts through direct engagement. The usefulness of dialogue and conversation in national inclusivity efforts for students with disabilities in higher education also deserves consideration.

## Limitations

The authors acknowledge that whilst the participatory approach taken to this research excavated rich data, it remains context bound. As is the case with qualitative research, our real-life experiences, sense-making and interpretations are of a subjective nature. In addition, the research findings represent a snapshot in time.

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# PART 2

## STUDENT'S PERSPECTIVES

# CHAPTER 6

## FROM OBSESSIVE-COMPULSIVE DISORDER (OCD) TO PHD

Richard Vergunst

### Abstract

Universities globally, including those in South Africa, have recently been experiencing an increase in enrolment of students with invisible disabilities. However, there are few available South African studies which have documented the learning experiences of students with invisible disabilities, as most studies continue to focus on exploring the experiences of students with visible disabilities. In this chapter, Richard Vergunst draws on his personal experiences of coping with doctoral studies as someone living with obsessive-compulsive disorder (OCD). In discussing this, the author merges his personal experiences with disability theory. He reflects on various challenges which slowed the completion of his doctorate, including how his disability would sometimes negatively impact on his motivation to focus on his studies, his self-confidence, and the side effects of taking OCD medication, such as memory loss. He furthermore discusses the value of the support he received from his supervisor, who was aware of disability inclusion issues, and was thus understanding and empathetic towards him. Vergunst also comments on his decision to self-disclose his disability, and encourages other students with disabilities to follow suit, as this enabled him to receive appropriate reasonable accommodations from both the institution as well as his supervisor. He emphasises the fact that students with invisible disabilities experience unique challenges which potentially negatively impact on their academic performance in higher education. This chapter recommends that South African universities transform their practices to create opportunities for more open relationships and personal interaction between students with disabilities and relevant stakeholders, especially lecturers, encouraging more students with invisible

disabilities to self-disclose their disabilities, as well as providing appropriate reasonable accommodations to students with disabilities if this group is to succeed academically.

## Introduction

Living with a disability while at university is an experience that is seldom shared with others. Frequently, the person with a disability may feel isolated and not heard when it comes to the stressors and dynamics of having a disability whilst being a student. This is especially true for students with invisible disabilities, and, in particular, psychosocial disabilities. This chapter is an attempt to discuss how someone with a psychosocial disability can manage the university experience by merging a personal story and some of the existing literature on disability theory. The hope is that my voice will be a catalyst for further awareness and discussion in this very pertinent but underrepresented issue in higher education.

## Invisible disabilities in higher education

Although there has been much research on the needs of students with more visible disabilities, the unique needs of students with invisible disabilities have received less attention (Mullins and Preyde 2013). Invisible disabilities include psychosocial disabilities, attention deficit disorders, and learning disabilities, and are so called as they are less visible to the observer than physical, sensory, or mobility disabilities. Students with so-called invisible disabilities are the fastest growing student population group. Persons with invisible disabilities may be subject to more misconceptions and stereotypes regarding the legitimacy of their disability and their need for support and protection (Wolf 2001). Mullins and Preyde (2013, 147), in the first study to examine the experience of having an invisible disability within a university setting, write, '[h]aving a disability that is invisible can make it easier for these students to be treated normally, it also means, however, that the validity of the disability can be questioned and that others may not understand the full extent of their limitations'. So-called invisible disabilities require different types of adjustments and present unique challenges in education settings.

## Psychosocial disabilities and higher education

Although a relatively new area of study, research is beginning to accumulate on the higher education experiences of persons with psychosocial disabilities (Collins and Mowbray 2005). Students with psychosocial disabilities continue to experience educational barriers and they tend to have deficits in attention, planning and organisation, memory, higher order conceptual thinking, and output fluency (Wolf 2001). This could potentially have an impact on their academic performance. According to Clouder et al. (2016), there is a need for university staff development, specifically with respect to responding to the needs of students with psychosocial disabilities.

As Mullins and Preyde (2013) mention, the most effective way of assessing the needs of students with disabilities is to be in direct consultation with them. In response to this, along with the fact that there are only a few studies in South Africa looking at students' experiences with disabilities, and that internationally psychosocial disabilities in education have received less attention than other disabilities (particularly at a university), this chapter is about my personal experience of having a psychosocial disability at a university in South Africa.

## My psychosocial disability

A far back as I can remember, I have always suffered from a psychosocial disability—be it anxiety, depression, or obsessive-compulsive disorder (OCD). Despite going to doctors, physicians, counsellors, psychologists, and psychiatrists in my childhood, I was only formally diagnosed when I was 25 years old. My very first counsellor, who I consulted when I was 13 years old, said I had a 'vivid imagination' and was a 'perfectionist', but did not offer a formal diagnosis. I was finally diagnosed with OCD and depression in my mid-twenties. OCD is a psychosocial disability characterised by the presence of anxiety-provoking obsessions (intrusive and unwanted recurrent thoughts or urges) and subsequent compulsions (repetitive behaviours that are perceived as necessary to neutralise the intrusive thought or urge). This disorder can be debilitating, as the obsessions or compulsions can be time-consuming and can severely impair the individual's occupational and social functioning.

My experience with living with psychosocial disabilities was a wild, messy, and harrowing journey with many pitfalls and agonies. As well as having three psychosocial disabilities (anxiety, depression, and OCD), I also had more than one type of OCD, and this made the experience more multifaceted and complex. I had primarily two obsessions and compulsions—the fear of hurting or killing people while driving, and the fear of HIV/Aids. The multiple obsessions and compulsions were at times very debilitating, and on occasion I could not function at all. They were also very often associated with deep depression. I was hospitalised at one stage due to the effects of OCD and depression, and I am still on heavy chronic medication to alleviate the symptoms.

Let me give you one of many, many examples. This example attempts to illustrate the intensity and debilitating effects of having OCD while at university. I needed to attend a meeting in town one evening, and on my way there, I had what I call a major OCD attack. I was driving on the freeway and suddenly thought that I had killed a pedestrian who may have been walking on the freeway. I initially continued towards town but was obsessing that there was someone lying in the middle of the freeway hurt or even dead. These obsessions were extremely intense and eventually I decided to turn around and check by driving past the 'scene'. I did this, saw nothing, and continued again on my way to town. However, the obsession, despite being relieved for a few minutes, came back and I thought that maybe I did not check properly. And so, this time I went back and decided to park my car on the side of the freeway and check on foot. This resulted in me walking up and down the middle of the freeway in the rain, cars speeding past, checking under trees and rocks and in the grass to see if there was any evidence of an accident. This lasted about thirty minutes, ending with me being drenched and extremely anxious. The compulsions of checking did bring immediate relief to me, but it was short-lived. I was able, eventually, to get back into my car, but then another obsession entered my mind: that

I had blood on my shoes (from the 'accident'), that I was now going to contract HIV/Aids, that I would walk into my family home with blood on my shoes, my family would then also contract HIV/Aids, and that we would all die. By this time, I was late for my meeting (for the first time ever) and I decided to go home despite my anxiety about the blood. On my way home, my obsessions with the 'accident' grew again and I was compelled to go back for the third time to the 'scene' and carry out more compulsions. Eventually I was able to get home, but once home I obsessed over the HIV/Aids resulting in me compulsively cleaning my shoes, compulsively cleaning the passages where I walked in the house and eventually washing my hands compulsively. Although not as intense, these obsessions and compulsions lasted for a few days, resulting in depression. It was after this experience that I eventually decided to go to another psychologist who diagnosed me for the first time with OCD.

The impact of my psychosocial disability at university was huge. Initially, I used my then-undiagnosed OCD to my advantage—my symptomology was my academic approach and performance and I used my obsessions and compulsions to carry out my academic work. I obsessed that I needed to work extremely hard, every minute possible, to perform well academically. This resulted in me working compulsively (but, in my opinion, rather ineffectively) on my studies. I would work on my studies every waking minute, and would very sparingly have free or relaxing time for myself. My fear of hurting and killing people on the road started in my Honours year, and in my Master's years the HIV/Aids issue was incorporated into my OCD. When I was finally diagnosed by a psychologist, I felt major relief, as, for the first time, I could put a label on what I was experiencing, rather than believing that it was me just being me. That relief is still tangible to this day.

However, even after being diagnosed, my PhD journey was also tainted by my OCD and depression. Firstly, I lost a great deal of time due to the time I wasted on my obsessions and compulsions. I would spend hours either obsessing or carrying out compulsive behaviours in order to alleviate my anxieties; time that I should have spent on studies I would spend lying on my bed obsessing, or I would be out performing compulsive acts. My OCD was very time-consuming and expensive in terms of petrol spent when compulsively driving around to check if I had hurt or killed someone on the road. Secondly, the related depression and anxiety made it difficult to focus and carry out my studies effectively. There were times when my mood was so low that I found it difficult to study and apply myself academically. Thirdly, my OCD and depression made it difficult to motivate myself to complete my studies. I was obviously more motivated to alleviate my debilitating anxieties and depression than to fulfil my study obligations. Life, and not killing people, were more important than writing exams or theses. Fourthly, I had a serious lack of self-confidence due to my 'mental illnesses'. How could I be self-confident if I was not 'normal'? This is what the literature calls self-stigma—stigmatising yourself due to your perceived lack of self-worth resulting from your disability.

Finally, the negative side effects of the heavy chronic medication need to be mentioned. The medication that I took through this journey made me very tired and drowsy. I needed to sleep more than normal, and so an extra limitation was placed on my study-time. Loss of focus and concentration were also side effects. I remember that at times in my PhD supervision meetings I would lose focus and concentration. Short attention span was another side effect—I was unable to work for long periods of time in one stretch. I needed to work in short spells with many breaks. Lastly, my memory has also been affected—since being on medication, my memory is not as sharp as it used to be.

All these issues are supported by the extant literature. Students with psychosocial disabilities may experience intermittent disruptions, of varying intensity, to their learning throughout the academic year, caused by fluctuating difficulties affecting their energy, mood, and motivation, together with negative effects of medication, difficulty in negotiating social relationships, and lowered levels of academic confidence (Venville et al., 2016). These may not be obvious to outsiders who do not fully understand the dynamics of having a psychosocial disability, and the absence of obvious disability may make it more difficult for the student to seek accommodations.

## Accommodations

According to Mullins and Preyde (2013), issues related to an invisible disability require different types of adjustments and accommodations with unique challenges. They say that the unique needs of students with psychosocial disabilities have received less attention, and have been the focus of less research than other forms of disability.

It was difficult for me to think of any accommodations from the university during my undergraduate and Honours years, since at that time I did not believe that I had a psychosocial disability, as no one was able to diagnose it. I thought that what I was experiencing was normal and appropriate, and that there was therefore no need for any accommodation on the part of the university. Following my diagnosis during my Master's year, I did not think of disclosing and seeking accommodation—in fact it did not cross my mind that accommodation was available, nor did I believe that it was applicable to me. The university did not market or advertise that service back in 1994, so, to my knowledge, seeking accommodation was not even an option for me. I just had to work through it myself with my family, psychologist, and psychiatrist.

Fifteen years later, I started my PhD at Stellenbosch University. There had been significant developments concerning issues of disability and education—not that I knew much about the opportunities available to me. Universities were slowly starting to show greater commitment to the inclusion of students with disabilities, creating, among other initiatives, organisations serving students with disabilities, and putting in place policies and rules that establish and regulate their rights (Moriña et al. 2015).

My PhD journey with regards to my psychosocial disability went a little differently because of these advances. Trammell and Hathaway (2007, 6) describe students' decisions to seek help as 'complex, multi-layered, and highly correlated to the climate and disability environment on campus, as well as to personal factors related to motivation, which vary from student to student'. To my mind, there are three aspects of accommodation that are important for persons with psychosocial disabilities: 1) self-disclosure, 2) open relationships and 3) individualised approaches.

I had met my supervisor 15 years earlier when he taught me at Honours level. A very good relationship had already been established between us, and I trusted and respected him. In other words, I felt safe to self-disclose my condition to him from the very beginning of the student-supervisor relationship. It felt quite normal and natural to do so because I felt safe, supported and heard. This may have been very different with another supervisor. His response was totally appropriate—sensitive and empathic. And this, in my experience, was the beginning of a wonderfully open and honest communication between the two of us.

I had to self-disclose if I wanted any accommodation from my supervisor or the university. Not that I expected or felt that I deserved any accommodation, as I was not used to this approach during my previous three degrees. Self-disclosure is thus the first step in the process of accommodation at university level. However, there is a reluctance on the part of students to disclose their disabilities for fear of being labelled or stigmatised. As Yssel et al. (2016) put it, to receive accommodations, students must self-disclose, but some opt not to do that. This, I think, is one of the main barriers to accommodation—the fear of disclosure by the student. Related to this notion of self-disclosure is self-advocacy—defined as an act that a person with a disability engages in to demand support (Test et al., 2005). Research over the last two decades has established that self-advocacy is an important skill for students with disabilities to acquire to achieve successful outcomes (Roberts et al. 2016). Self-advocacy is associated with the ability to embrace disability as part of one's sense of self (Kimball et al. 2016).

As I alluded to earlier, my relationship with my supervisor was based on open and honest communication, and I encountered no attitudinal barriers. Some scholars have concluded that attitudinal barriers have the greatest negative impact on the learning and academic achievement of students with disabilities (Borland and James 1999; Moswela and Mukhopadhyay 2011). Again, the fact that there were no attitudinal barriers from the supervisor during my learning process made it that much easier for me, resulting in a successful outcome to my studies. Studies have shown that lecturers or supervisors are key role-players when it comes to enabling or hindering students throughout the learning process (Molina 2016). My supervisor's warm approach to my disability is distinct from the 'chilly climate' that students with disabilities often experience in higher education (Kimball et al., 2016, 245).

A fear of the unknown, prejudice, and ignorance of lecturers have been found to form communication barriers with students with disabilities (van Jaarsveld and Ndeya-Ndereya 2015). Not in my case—my supervisor was well aware of psychosocial disabilities, and had no prejudices. This facilitated the academic relationship immensely. Beilke and Yssel (1998) support this when they say that the lecturer's role in establishing a caring, mentoring relationship within the context of the university is of utmost importance. I do not think I would have been able to complete my thesis successfully if it was not for this relationship between my supervisor and myself. Regardless of the intention, distancing behaviour between lecturer and student marginalises students with disabilities, displays a lack of respect for their human dignity and deprives them of a sense of equality in relation to other students. Moreover, a lack of connectedness between student and lecturer could have a detrimental effect on the motivation and consequently the academic performance of students (Van Jaarsveldt and Ndeya-Ndereya 2015).

Students with disabilities in higher education frequently need support to help them succeed in their studies (Fleisher et al. 2013). In their study, Moriña et al. (2015) report that support from lecturers tends to have a very positive impact on students' academic performance. Support is an important factor in facilitating more favourable academic outcomes. The support by the supervisor has had a significantly positive impact on the student's progress and ultimate accomplishment of obtaining a PhD. This cannot be overstated. Practical support as well as emotional support by the supervisor plays a significant role in the completion of the degree.

There were occasions when I experienced a severe slump in my focus, motivation, and energy regarding the completion of my thesis due to my depression and OCD. If it was not for the sensitive and caring response of my supervisor, I think I would have terminated my PhD. My supervisor and I were able to discuss the dynamics and issues and reset appropriate processes, goals, and incentives for me. This was paramount to me completing my thesis. This was due to two factors—my self-disclosure, and my supervisor having an empathic and supportive approach to my situation which enabled us to build a supportive relationship.

The third factor that I found to be very important was that my supervisor integrated an individualised approach to our circumstances—he treated me as a unique individual with specific needs. Hadjikakou and Hartas (2008) concur that an individualised approach is required to identify and provide appropriate support needs for students with disabilities, rather than providing general support based on the type of impairment.

## Conclusion

Despite policies and procedures at universities being progressive and useful, this is insufficient. We need to address these issues of inclusion at a deeper level as well; we need an individualised approach and accommodation of every student's unique needs. It is not necessarily the concrete or formal structures and policies for inclusive education that are important to facilitate learning for students with psychosocial disabilities. It is the more subtle, social, and underlying human interactions—the awareness and acknowledgement of the student by the university staff—that are paramount. It is advocated here that these interactions are more important and effective than the formal structures that are put in place by universities.

The voice of the student must be heard. Research in the area of inclusion and disability in higher education argues for the need to include the voices of this population group in assessing their needs, addressing barriers, and evaluating subsequent provision (Fuller et al. 2004). Research in higher education suggests the need for educationalists to show greater understanding and awareness of the lived experiences of students with disabilities (Gibson 2012). Implementing effective interventions in general education increases the chances of success for students with disabilities (Reichrath, De Witte, and Winkens 2010). Universities are starting to introduce programmes to include students with disabilities further, and these usually require the implementation of specific rules and regulations. But it is not enough; inclusion and transformation must also happen on an individual and personal level so that students with disabilities have the opportunity for positive, supportive relationships with lecturers and supervisors at university.

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# CHAPTER 7

## SUCCESSFULLY NAVIGATING HIGHER EDUCATION INSTITUTIONS FOR INCREASED PARTICIPATION: THE EXPERIENCES OF STUDENTS WITH DISABILITIES AT A JOHANNESBURG-BASED UNIVERSITY

Jacqueline Moodley and Tinovimba Patsika

### Abstract

To date, research exploring the experiences of students with disabilities in South African higher education institutions has largely focused on the barriers which hinder the academic participation and success of this group. This academic focus has recently been criticised for being too narrow, as, in practice, the full participation in university life for students, including students with disabilities, also involves aspects of social inclusion, especially participation in extra-curricular activities like sports. In this chapter, Moodley and Patsika discuss the experiences of student athletes with disabilities at one South African university to identify the factors that contributed to the facilitation of their participation in sport at this institution. Participation in sport creates opportunities for growth and social interaction. The benefits of participating in sport includes opportunities to receive bursaries, to learn self-discipline, and to challenge the concept of ‘normalcy’. The chapter shows how university sports divisions and disability units can play an important role in creating an enabling environment for students with disabilities to take part in sporting activities. The authors recommend that South African universities take the social inclusion of students with disabilities seriously, and work harder at removing potential barriers which hinder their participation in extra-curricular activities, such as sport, at both recreational and competitive levels, as this enhances their sense of belonging at the university, and can also facilitate professional sport career opportunities post university.

## Introduction

In South Africa, approximately 2 per cent of adults with disabilities reach tertiary education, and approximately 22 per cent have no education at all (Moodley 2016)and while South Africa ratified the United Nations Conventions for the Rights of People with Disabilities, these actions have yet to translate into meaningful changes for persons with disabilities. To investigate the status of educational attainment, this article uses South Africa's National Income Dynamics Study to analyse the disparities in education for adults with and without disabilities. Education is a key mechanism of leverage for functionings. The findings show that persons with disabilities fare worse in educational attainment than persons without disabilities, but that race and geographic location play a larger role in predicting educational attainment than disabilities. In addition, age also contributes to educational disparities. The findings of this study are integral in the call from the Presidency to 'strengthen the country's response to the needs of [persons with disabilities] … and to monitor progress' of educational attainment for persons with disabilities (20-year review, 2014, p. 73. Roux and Burnett (2010) contend that low tertiary enrolment rates can stem from the distinction between mainstream and special needs schooling, making it difficult for students with disabilities from special needs schooling to be integrated into tertiary education where distinctive environments do not exist. Historically, under apartheid, persons with disabilities were excluded from society and denied their social, political, and economic rights (Department of Social Development 2016). Democratic policies in South Africa have since identified persons with disabilities as a target group to promote economic inclusion and facilitate access to education. However, structural and attitudinal barriers are highlighted in the literature as forces which prevent students with disabilities from entering higher education institutions in South Africa (Engelbrecht and Beer 2014; Matshedisho 2007; Mutanga 2015)only 2.8% of disabled persons have access to higher education. The aim of this study was to determine if a group of students, living with a physical disability, experienced constraints with regard to access to a South African higher education institution. This study, following a two-phase sequential mixed method approach, consisted of a questionnaire survey, a focus group discussion, and individual interviews. It was found that students living with a physical disability experienced constraints relating to the accessibility of the relevant higher education institution. Since access constraints affect the lives of students living with a disability, it is necessary to provide guidelines to universities on how to address these challenges.","DOI":"10.1080/18146627.2014.935003","ISSN":"1814-6627","author":[{"family":"Engelbrecht","given":"L."},{"family":"Beer","given":"J. J.","dropping-particle":"de"}],"issued":{"date-parts":[["2014",10,2]]}}},{"id":215,"uris":["http://zotero.org/users/159279/items/UQEVFPZN"],"uri":["http://zotero.org/users/159279/items/UQEVFPZN"],"itemData":{"id":215,"type":"article-journal","title":"Access to higher education for disabled students in South Africa: a contradictory conjuncture of benevolence, rights and the social model of disability","container-title":"Disability & Society","page":"685-699","volume":"22","issue":"7","source":"Taylor and Francis NEJM","abstract":"The structures of support services for disabled students in the South African higher education system find themselves in a contradictory conjuncture of rights, benevolence and the social model of disability. To elucidate this argument, this paper (a.

From a human capability perspective, limited education results in a limited capability set, which deprives persons with disabilities of their freedom to help themselves and also to influence the world" (Sen 1999, 18). If participation in education alone is deemed challenging for persons with disabilities, the potential for participation in broader aspects of university life, such as sport, seems impossible. Yet, some persons with disabilities are able to integrate successfully into university as well as participate in a number of extra-curricular activities, such as sport and other societies.

In the broader social environment, familial support, and pre-university experiences are known to shape the university experiences of students with disabilities (Mutanga 2015)"publisher":"University of the Free State","publisher-place":"Bloemfontein","event-place":"Bloemfontein","URL":"http://scholar.ufs.ac.za:8080/xmlui/bitstream/handle/11660/3870/MutangaO.pdf?sequence=1","author":[{"family":"Mutanga","given":"O"}],"issued":{"date-parts":[["2015"]]},"accessed":{"date-parts":[["2017",1,1]]}}}],"schema":"https://github.com/citation-style-language/schema/raw/master/csl-citation.json"} . In relation to familial support, the difficulties in caring for persons with disabilities is described as financially burdensome, since additional costs are associated with having a disability (Sen 1985; Watermeyer et al. 2006). These costs are inclusive of additional medical care required, rehabilitative costs, special needs education, and the costs of care required by persons with disabilities. Mutanga (2015) describes how some students with disabilities who enter higher education institutions usually have positive experiences due to family support, such as, for example, an instance where a mother of a student lived with her child at a university residence to assist with daily activities. Viewed from a human capability perspective, these kinds of additional resources are required for persons with disabilities to be able to lead lives that enable optimal participation (Sen 1985).

Pre-university experiences are also known to determine student success in higher education. Mutanga (2015) and Tugli et al. (2013)"publisher":"University of the Free State","publisher-place":"Bloemfontein","event-place":"Bloemfontein","URL":"http://scholar.ufs.ac.za:8080/xmlui/bitstream/handle/11660/3870/MutangaO.pdf?sequence=1","author":[{"family":"Mutanga","given":"O"}],"issued":{"date-parts":[["2015"]]},"accessed":{"date-parts":[["2017",1,1]]}}},{"id":183,"uris":["http://zotero.org/users/159279/items/3KJ66S7N"],"uri":["http://zotero.org/users/159279/items/3KJ66S7N"],"itemData":{"id":183,"type":"article-journal","title":"Perceptions of students with disabilities concerning access and support in the learning environment of a rural-based university","container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years describe the difficulties that students with disabilities have in adjusting to university life if they were able to attend well-resourced special needs schools. In these instances, university resources are often perceived to be insufficient for students to feel adequately supported in higher education institutions. By contrast, Mutanga (2015) reports that students from less fortunate backgrounds are often appreciative of the support services provided by universities.

In exploring university environments in more detail, Tugli et al. (2013)"container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years highlight the need for special support within university environments to enable full participation of students with disabilities. The current climate on transformation of South African higher education institutions is seen to exclude students with disabilities from diversity and social justice initiatives. Students are known to face challenges such as a lack of reasonable accommodation for persons with disabilities. Furthermore, a lack of assistive devices required for the learning needs of students is experienced (Buthelezi 2014; Engelbrecht and Beer 2014; Fuller et al. 2004)"abstract":"For physically challenged students, inequalities in further education begin with inequalities that have shaped the whole schooling system in South Africa. The limited provision that exists for physically challenged students at further education and training colleges in KwaZulu-Natal Province, especially black physically challenged students, means that for these students there is a very high level of exclusion from the education system. Many students with physical challenges still need an ally even in their basic accommodation.\r\nThe focus of this research was on exploring challenges experienced by physically challenged students at “Mango” (pseudonym. In their research at the University of Johannesburg, Roux and Burnett (2010) expressed that the views and experiences of students with disabilities at the University of Johannesburg were largely ignored. However, the same university was described by Tugli et al. (2013)"container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years as one of the most privileged in the country, which enabled the institution to promote equal participation of students with disabilities.

Investigations by Ramakuela and Maluleke (2011) in the Free State region described that 80 per cent of impaired students felt a sense of intolerance and resentment, resulting in feelings of rejection from non-disabled peers, university staff and the institution as a whole. Factors leading to the sense of rejection included inadequate learning materials and an inaccessible environment. These barriers were all present despite policy provisions for disability [to] be integrated into all facets of planning, recognising that there is no one-size-fits-all approach' (Department of Social Development 2016, 41).

Mutanga's (2015) inquiry into the University of the Free State and the University of Venda found that physical access within the universities, staff awareness of disability issues, and poor assessment procedures during examinations were some of the factors which contributed to students with disabilities feeling excluded from university life. Buthelezi (2014)"abstract":"For physically challenged students, inequalities in further education begin with inequalities that have shaped the whole schooling system in South Africa. The limited provision that exists for physically challenged students at further education and training colleges in KwaZulu-Natal Province, especially black physically challenged students, means that for these students there is a very high level of exclusion from the education system. Many students with physical challenges still need an ally even in their basic accommodation.\r\nThe focus of this research was on exploring challenges experienced by physically challenged students at "Mango" (pseudonym found these same challenges in her study which explored the experiences of students with disabilities at one training college in the KwaZulu-Natal province.

To date, research on students with disabilities in higher education institutions in South Africa is rather fragmented. The available investigations concentrate largely on the barriers to participation in academic aspects. These barriers are both largely structural and attitudinal. Participation in university life, however, goes beyond academia to include access to recreational facilities and participation in extra-curricular activities. These extra-curricular activities scored the lowest in terms of user-friendliness at the University of Venda, a rural-based South African university (Tugli et al. 2013)"container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years. With the literature pointing to insufficient integration of students with disabilities in core academic activities, participation in extra-curricular activities at university seems unattainable. Yet, some South African universities can facilitate the participation of students with disabilities in sport, for instance.

In this chapter we investigate the experiences of students with disabilities at a tertiary institution who also participate in sport. We explore students' support structures, intrapersonal factors that drive their progression through university, and the role of the university in assisting their participation. The rationale for our approach is that if students can participate in sport, they are assumed to have been successful in navigating the university environment to increase their participation in academia and extra-mural activities. Learning their stories enables us to understand what contributes to the integrated participation of students with disabilities.

Sport is described by Swartz et al. (2016) as a positive experience that allows athletes with disabilities to reframe their own identifies as well as feel empowered and included. The limited research on athletic participation of students with disabilities in higher education institutions points to the fact that sport enhances social support and integration (Roux and Burnett 2010). In their study, Blinde and Taub (1999) describe how students with disabilities in the United States of America felt more in control of their lives through participating in sport, and that empowerment emerged in three areas: (1) students felt they were social actors in their own lives; (2) sport facilitated a means to attain personal goals; and (3) participating in sport facilitated social integration.

Understanding involvement in sport from a human capability perspective enables us to identify the freedom to participate in sport as an expansion of the capability set of students with disabilities, resulting in holistic development (Roux and Burnett 2010; Sen 2003; Tugli et al. 2013)"page":"41-58","event-place":"New Delhi and New York","author":[{"family":"Sen","given":"A.K."}],"editor":[{"family":"Fuduka-Parr","given":"S"},{"family":"Shiva Kumar","given":"A.K."}],"issued":{"date-parts":[["2003"]]}}},{"id":183,"uris":["http://zotero.org/users/159279/items/3KJ66S7N"],"uri":["http://zotero.org/users/159279/items/3KJ66S7N"],"itemData":{"id":183,"type":"article-journal","title":"Perceptions of students with disabilities concerning access and support in the learning environment of a rural-based university","container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years. To understand this conceptualisation further, disability and participation in sport is explained using the Human Capabilities Approach.

## The Human Capabilities Approach and disability

Dubois and Trani (2009) define disability as a capability deprivation. To understand this view, the language of the Human Capabilities Approach needs to be explained. The approach differentiates between 'functionings' and 'capabilities'. 'Functionings' describe what a person *is* able to do (Sen 2003). 'Capabilities', on the other hand are the functionings that a person *could* possibly achieve. Robeyns (2003, 63)"container-title":"Feminist Economics","page":"61-92","volume":"9","issue":"2-3","abstract":"This paper investigates how Amartya Sen's capability approach can be applied to conceptualize and assess gender inequality in Western societies. I first argue against the endorsement of a definitive list of capabilities and instead defend a procedural approach to the selection of capabilities by proposing five criteria. This procedural account is then used to generate a list of capabilities for conceptualizing gender inequality in Western societies. A survey of empirical studies shows that women are worse off than men on some dimensions, better off on a few others, and similarly placed on yet others, while for some dimensions the evaluation is unclear. I then outline why, for group inequalities, inequalities in achieved functionings can be taken to reflect inequalities in capabilities, and how an overall evaluation could be arrived at by weighting the different capabilities.","DOI":"10.1080/1354570022000078024","ISSN":"1354-5701","shortTitle":"Sen's Capability Approach and Gender Inequality","author":[{"family":"Robeyns","given":"Ingrid"}],"issued":{"date-parts":[["2003",1,1]]}}}],"schema":"https://github.com/citation-style-language/schema/raw/master/csl-citation.json"} distinguishes between functionings and capabilities as similar to the difference between an achievement and the freedom to achieve something". Another central concept of the Human Capabilities Approach is that of 'freedom'. Sen (1999, 18) describes 'freedom' as an aspect that 'enhances the ability of people to help themselves'. Thus, describing disability as a capability deprivation indicates that persons with disabilities have a lack of freedom in relation to what they *could* possibly achieve as a result of their disabilities (Trani et al. 2011).

An advantage of using the Human Capabilities Approach in Disability Studies is that it allows researchers to investigate the interaction between the social environment and persons with disabilities. This environment can either inhibit or advance the development of persons with disabilities (Sen 1999). In this way, persons with disabilities are placed on the broader spectrum of human development to encompass the many areas of development which they may find valuable (Trani et al. 2011).

Pertinent to this study, being at university and participating in sport are regarded as functionings. The freedom to participate in these activities are an end in itself, but also enables further development in that tertiary education and professional athletics can facilitate career opportunities for persons with disabilities. These activities can therefore lead to an expansion of capabilities of persons with disabilities.

Trani et al. (2011) state that adopting the Human Capabilities Approach changes the focus of policy to pay attention to the expansion of human capabilities while respecting people's values. This aspect is of particular importance since Lyner-Cleophas et al. (2014) highlight the need for better policy development in higher education on inclusive practice and call for greater implementation of policies. Therefore, this chapter aims to adopt a Human Capabilities Approach to understanding the view of students with disabilities at a Johannesburg-based university. While some time is spent reflecting on how the university can improve to assist students, the main purpose of this chapter is to identify factors that have facilitated participation of students with disabilities at university.

## Methodology

The collection of information about the experiences of students with disabilities was done using a qualitative research design. Qualitative research facilitates deep reflection and conversation with participants that gives full, complex, and meaningful pictures of ideas, viewpoints, and events from the participants' perspective (Jaeger 1997). Qualitative research is shaped by the position that an individual's understanding of the world is based on his/her personal assumptions, biases, and prejudices (Bless et al. 2013). The focus of this study was to establish how students have navigated through tertiary system to successfully balance their studies and sporting careers. A qualitative approach allowed these stories to be interpreted from their frame of reference through inductive understanding (Bless et al. 2013).

## Research site

This study was conducted at a Johannesburg-based university, which had recently invested a large number of resources into upgrading facilities for students with disabilities. This university was selected because of its practices in incorporating students with disabilities into the South African tertiary sector. To comply with the regulations put forward by the White Paper on the Rights of Persons with Disabilities (Department of Social Development 2016), the university itself has a Policy on Support Services for Students with Disabilities.

To implement the policy strategies, the university has a Disability Office that plays a central role in providing for assistance to students. This office monitors aspects such as accessibility to facilities for students with special needs. These facilities range from parking spaces to adjustments required in lecture theatres. In addition, support is available for the conversion of lecture material to alternate formats, such as braille or audio recordings. Sensitivity training to staff and counselling for students with disabilities are also available. Over the years, the Disability Office has also implemented disability awareness days (Department of Basic Education 2009).

In addition to the Disability Office, the sport division for students with disabilities has played a central role in the inclusion of athletes with disabilities. The investments made by the university have resulted in both acclimation and numerous awards for both the university's ability to accommodate students with disabilities and for the students participating in sport. From these accolades it could be inferred that the environment is a model from which lessons on the inclusion of students with disabilities could be learned.

## Population and sampling

The study population comprised of all students with disabilities who participated in sport at the selected university. Purposive, homogeneous sampling was used to draw a sample of four students from this population through the assistance of the Division of Sport for Students with Disabilities. It is important to note that we do not view the construct of disability as homogeneous. Rather, the homogeneity we refer to stems from the fact that all students chosen were student athletes with physical disabilities. Thus, the findings cannot be considered accurate for student athletes with other types of disabilities.

## Data collection and instrument

Individual interviews are a more personal method of collecting information and enable participants to be forthcoming about their views (Harrell and Bradley 2009; Valenzuela and Shrisvastava 2008). According to Berg (1995), face-to-face interviews help identify any non-verbal cues that might indicate a person's deeper feelings, e.g. through facial expressions, rubbing hands, and avoiding eye contact. This would to an extent assist the researcher in the analysis of all the information collected.

The interviews lasted approximately one hour. Initial questions on past histories and backgrounds were asked to develop rapport (Ryan and Dundon 2008). The questionnaire included inquiries into the personal experiences of disabilities and experiences within the university systems, drawing on previous studies (Roux and Burnett 2010; Mutanga 2015; Tugli et al. 2013). However, the exploration of support structures available within families and communities, as well as participating in extra-curricular activities, provided novel information on the experiences of students with disabilities within higher education institutions. To ensure that the questionnaire adequately captured this information, it was piloted with a student prior to data collection.

## Data analysis

For the qualitative data, a thematic analysis was conducted using ATLAS ti., a data management software system that enables researchers to conduct qualitative analysis electronically. Thematic analysis refers to the identification of patterns within the data (Braun and Clark 2006). Braun and Clarke's (2006) process of thematic analysis involves six steps, namely: (1) To familiarise oneself with the data; (2) To conduct initial coding across collected data; (3) To collate the codes into themes; (4) To review themes by generating a thematic map; (5) To define and name themes and (6) To produce a report through choosing relevant extracts, final analysis and presentation of findings.

The main themes identified were in line with the literature on familial support and individual capabilities, as well as university policies, support mechanisms and challenges for students with disabilities (Roux and Burnett 2010; Mutanga 2015; Sen, 2003; Tugli et al. 2013). In terms of the themes extracted from the data, we focused on: (1) student backgrounds and experiences; (2) academic and recreational participation at university; (3) participation in sport; (4) accomplishments and attributes to success; and (5) recommended areas for improvement within the university system.

## Ethical considerations

Ethical clearance to conduct this research was obtained from Research Ethics Committee at the selected university. The maintenance of research ethics is a vital element of any research study (Murphy and Davidshofer 2005). It is the researchers' obligation to protect the rights and values of participants. To do this, consent was sought from all the participants. They were given all the details about the study and were made aware of the voluntary nature of their participation and their right to withdraw at any moment. In addition, the confidentiality of information given and anonymity in the reporting of findings were guaranteed. To ensure confidentiality and anonymity, the university where the research took place was not mentioned. Furthermore, interview participants were only known to the researchers. The participants were also assigned pseudonyms as to ensure that they cannot be identified.

# Findings

## Participant profiles

The four participants who were interviewed for this research study are described in Table 1.

Table 1: Participant profiles

| Pseudonym | Degree | Age | Race | Gender | Type of disability |
|---|---|---|---|---|---|
| John | Business Management | 23 | White | Male | Cerebral Palsy |
| Paul | Journalism | 19 | White | Male | Physical (Club foot) |
| Sipho | Business Information Technology | 20 | Black African | Male | Phocomelia |
| Thando | Marketing Management | 21 | Black African | Female | Spina Bifida |

When questioned about their hopes and aspirations for their futures, Thando specifically spoke about her strong desire to go into strategic marketing within companies like Unilever or Procter and Gamble. Sipho, on the other hand, mentioned his desire to enhance his IT skills at big service providers such as Vodacom, Oracle, and the Microsoft Corporation.

All students who were interviewed were recipients of bursaries that enabled them to attend higher education. The bursaries attained by the students were accessed from the institution's sports bursaries, the National Student Financial Aid Scheme, and the Department of Labour Bursaries for persons with disabilities. In terms of what these bursaries provide, Thando mentioned that:

> The bursaries are really good. I mean they pay for my registration and tuition as well as accommodation on campus. Oh yes! There's the money for books and there's also the card that we can use to buy food and groceries at the Pick n Pay. (Thando)

The recruitment processes for the participants were all similar in the sense that they were recruited on the basis of them passing their matric as well as their good track record in sport participation. Representatives from the university's psychological services and career development department, as well as from the sport division, attended career days where they scouted potential students. Participants expressed that:

> Because of my disability and my participation in athletics [Paralympics], the university offered me a sport bursary to study. (Paul)
>
> My sporting activities opened up opportunities for me, and after meetings with the sports department I was recruited and offered a bursary. (John)
>
> The Disability Unit came and told us about the opportunities at the university and that's how I was able to apply…they told me about the Department of Labour's

> bursary for disabled people and they helped me apply. After passing my matric I was enrolled, received my bursary all through the help of the Disability Unit. (Thando)

The student athletes participate in a broad range of sport activities at the university. These include wheelchair basketball, track and field athletics, and swimming. Before we attempted to understand the more detailed experiences of these student athletes at the university, their backgrounds and support mechanisms that have enabled them to become active participants in their own lives were explored.

## Student background and experiences

All the students interviewed came from different backgrounds that resulted in different personal experiences while growing up, both within families and within communities. Understanding individual experiences of disability helps us identify factors which influence development and social interactions. Although the students did identify themselves as persons with disabilities, they also identified themselves as ‘normal’. Sipho said that:

> Sometimes I ask people what the point of walking is. Isn’t the point to get from point A to B, and if I can still do that in my wheelchair, then how am I different from you?

The narratives of the students revealed that the feeling of ‘normality’ had roots in having a strong family support structure. Across all the interviews, the students mentioned that their families instilled the belief in them that they could do anything that any other person could do. In acknowledgement of family support, students described their families in statements such as:

> I wasn’t treated any differently because my family believes that I am normal like everyone else, because I have achieved a lot of things that other people who see themselves as normal could not achieve, like getting to university and playing [sport] for the national team. (Sipho).
>
> [My family] have instilled in me that there is nothing different about me. So [my mother] would want me to do the chores that every other person would be required to do like washing dishes, washing my own vests when I came back home. I’d have to walk certain kilometers to get to school like everyone else, and when I would complain that I was tired, she would say there is nothing different about you. I’m really grateful for that, because had she not done that, I would probably be complacent and be a cry baby if she hadn’t raised me that way. So it was for my own benefit. (Thando)

With some families, the support structures also extended beyond the parents to immediate maternal or paternal families:

> With my mum…she also had her mother as a support structure, and she supported her while I was in hospital and she took care of me while I was in hospital. (Thando).

For Paul, there was greater feeling of being understood as he shared the same disability with his father. He therefore acknowledged that his family had experience in motivating him when he needed it:

> I share the same disability as my father. We both have club feet, the only difference is I only have one club foot. My parents accept, respect, and want me to live my live to the fullest. (Paul)

Moving to the broader community, including school experiences, the students who were interviewed reported mostly positive experiences within their communities. School experiences were generally encouraging, however, aspects such as commuting posed some challenges. Thando said:

> At home my mum doesn't have a car, so I have to commute and use taxis to get around. The people are sometimes very apprehensive when they see my wheelchair. They don't want to help me get into the taxi, so I usually use crutches. Although it's tiring, I have to use them to get people to be more comfortable around me and accept me. Although, also I get stared at a lot because, like right now, there's not much you can see, but once I'm off my chair then you can see the deformities and the parts that are protruding and all. So the stares have always been uncomfortable.

Despite Thando's description of her difficulty in commuting, she highlighted that in response to feelings of marginalisation in society, she was involved in raising awareness of disabilities and helped educate those around her:

> People who have not been exposed to disability within their own families need time to understand, as they are mainly driven by curiosity and sometimes confusion about how to actually help someone with a disability.

Despite being pioneers in disability awareness, students still faced challenges on an emotional level because of their disabilities. Issues of self-esteem, embarrassment, and a negative self-image were narrated during the interviews:

> I think everyone goes through self-esteem issues, especially women. But I think the disability added to it, and makes it worse because you think, okay everyone is complaining about stretch marks, but I have stretch marks plus a tiny and a big leg so that's a disadvantage. (Thando)
>
> My self-image is affected sometimes, because sometimes you feel like you don't belong here and that you are different from everyone else. That's when you have thoughts of isolating yourself, and [you] are not fully positive about yourself. (Sipho)

> Sometimes I think because I'm so disproportioned, I think that's the most embarrassing factor for me. (John)

These personal challenges, however, were not hindering, as students went on to say how they have learned to accept themselves and be confident with themselves. Personal acceptance was largely a result of their accomplishments in life. These accomplishments also encourage students to motivate other students with disabilities:

> I feel proud of myself because of what I have accomplished. [There are many] things I have come to accept and be confident in. (Paul)
>
> I drive them [other students] to do more with their lives…there are people who have nothing but still try to do something. (John)

Although students participating in this study had concrete family support while growing up, they were also exposed to challenges in communities and experienced internal struggles because of their disabilities. Students were still able to overcome their struggles. Their personal experiences in tertiary education, their experiences within the institution they attend, and the challenges they still experience, are presented next.

## Life at university: Academic and recreational participation

It was remarkable to note the enormous amount of positivity that emanated from the students when they spoke about university life. Integration into higher education was an encouraging experience for all the students. The Office for Students with Disabilities at the university offered invaluable assistance in integrating students. The students expressed that:

> Not knowing the campus felt like a big problem, but the Disability Unit was really helpful in orienting us in terms of information to do with courses and study venues and other internal stuff. (Thando)
>
> To help in my integration, the university was able to give me a lovely place to stay within the on-campus residences (John)
>
> My main support from the university has been through the [Disability Unit] this whole first year because they have helped me a lot when I have any problems with my sport and schoolwork also…and the writing centre assists a lot too. As for other support, most of my classes are wheelchair friendly and this makes things easier for me. (Sipho)

Following the initial assistance of the university in the early stages of integration into higher education, the students all acknowledged how the university has continued to play an important role in accommodating them through their studies and recreational participation. This included different kinds of support mechanisms such as structural and emotional support. In expressing her views of the support offered by the university, Thando was particularly vocal:

> So the Disability Unit comprises of an assistive device technologist, an educational psychologist, and there's a person who takes care of the academic side in terms of concessions for people who need extra time and all of that. And there's also a social worker. So, with the social worker we had check-in sessions throughout first year. We would go in and they would ask us about our progress and how we are adjusting to university life. They helped us a lot. They helped us a lot academic wise, how to manage our time, with punctuality and other things on the academic front. (Thando)
>
> On the sport side, we have [the sport manager] who finds out our accomplishments in sports, and also what our intentions are. She facilitates transport for us, our kits for our different sports, and she makes sure we have physio if we need it, and she checks if we go for training, and she also checks our progress. She is very hands-on. (Thando)
>
> Something that I can think about is at the lecture venues. We have desks that don't have any chairs, so your wheelchair can park nicely there and most of these desks are in front so you can be attentive of what's happening in class. (Thando)
>
> Also, to do with our writing of tests and exams, we are able to write these at [the Disability Unit] where if we need extra time—it's afforded to you, if you have a scribe then it's easier done at [the Disability Unit], if you're visually impaired—there's software that can speak to you and you can speak to it back in response. All of this under the university's expense, and I think that those avenues are very helpful to us persons with disabilities. (Thando)

Overall, the students had access to various support mechanisms made available by the university which allowed them to participate meaningfully in university life. Support mechanisms were academic, emotional, and recreational. The additional academic support for students included assistive devices, additional time for exams, and alternative formats for writing exams, as well as guidance on how to manage time and be punctual. Emotionally, psychologists and social workers were able to support students with disabilities in their needs when integrating into university, and for their needs during their time at university. On the recreational front, in relation to sport specifically, the availability of a sport manager who assists with facilitating sport, physiotherapy, and providing kits for these students is crucial in allowing students to participate in sport. These additional support resources were important in expanding the capabilities of persons with disabilities to enable greater participation. This is in line with Sen's (1985, 7) view that 'we must take note that a disabled person may not be able to do the many things that an non-disabled individual can, with the same bundle of commodities'.

## Participation in sport

The student athletes identified sport participation at the university as a natural progression from their participation in sport at high school. Through the university, students have been able to progress in their different academic disciplines and they said that sport had played major roles in their personal development. The following was said about participation in sport at university:

> Sport has opened up opportunities for me …as I've been an international athlete since 2011 and trained at the university's facilities for close to six years. It was a smart decision for me to participate in sport…The university has helped me to still travel and compete and still catch up with my studies. (John)
>
> When I qualified for the Nedbank National Championships for wheelchair basketball, the Sports Division helped me with my training as they allowed me [to] practice with them. (Sipho)
>
> The Sports Division recruited me in 2011, and they have been helping me with my training and transport to my events. They give me massages and ice baths at the track. That's all from the university. (Paul)

In addition to the practical aspects of being involved in sport, the students also relayed instances of personal growth through sport. This is what they said:

> When I was selected for the national team, the sport manager took me in and I started training at the university. They also offered transport to travel to all my games…Sport has opened up an avenue for me to be able to go to gym and be fit… and also allows me to officiate when there are trials and people have to be selected for provincial games…Sport has helped me with communication, because before I played sport, I was shy. But, here at university, I have gained confidence to even apply for jobs outside sport, like student assistant jobs. Sport also teaches you discipline. (Thando)
>
> Sport teaches you a lot of things. Commitment, time management and perseverance are some just some of the traits that you build being an athlete, helping me in my personal development. (John)
>
> It makes me a better person. Always wanting to strive for more. It gave me the skills to interact with people a whole lot better, to build bonds with them. (Sipho)

To further help students with disabilities, the Sports Division at the university had combined sporting clubs to accommodate both athletes with disabilities and those without disabilities. The students felt that this helped them a lot with their confidence as they received support and were motivated by working in the same environment as non-disabled athletes. This integration was seen as vital by one student, because although people may have differences, there was a lot of room for learning from each other. Thando said:

> You know when I think about the gym…where we all come together, I must say that I felt uncomfortable. But this is more personal for me. Like, if you have to get down on the mat, you feel like other people are looking at you and how different you look. So, you feel a bit uncomfortable, and so I always wrap a jersey around me, because most of my problem is my lower back, so I cover myself there. But, then again, people are always willing to help us with the gym equipment and

> putting stuff back or equipment adjustments and all. So, although it's a personal thing for me, seeing many people motivates you, and [you] always want to push harder. (Thando)

In line with the research conducted by Swartz et al. (2016), it was interesting to note that participation in sport contributed to personal development of student athletes with disabilities, over and above their innate ability to participate in sport at all levels, including the Olympics. Participation in sport contributed positively to athlete's confidence, discipline, interpersonal relationships, and integration of athletes with disabilities with those who do not have disabilities.

## Accomplishments and attributes to success

Since this chapter seeks to communicate the experiences of student athletes with disabilities and to identify the resources and mechanisms which contributed to their successful integration into university, recognising student accomplishments is important. The students themselves identified their biggest accomplishments to date as well as the attributes of their successes:

> My sport is my biggest success: the Rio and London Paralympics, as well as three World championships and medaling in two of them. My academics are also a success, and I'm looking to pass all my modules this year…[I have been led to this success by] communication, commitment, and support structures. (John)
>
> I'd say both are success…I have a sport and an academic bursary…My motivation is my parents, because of what they have done for me, and what they are still trying to do for me. (Paul)
>
> Getting to university is an achievement on its own, and there's not much to say about it since it's still only my first year. But my biggest achievements are in sports. I've played for Gauteng for five years and the national under-23 team. I was selected this year to play for the qualifiers in December, so I think sport has really been my biggest achievement…[I attribute this to] hard work. Like with sport, I have to wake up early and go to the gym. And also faith in God. I always pray before a game. (Sipho)
>
> My motivation is my good support structures from home and school. I think people believing in you is a part of it. Also not letting my disability be a factor and rising above it has truly been a great motivational factor. Looking at the situation at home (it's not very good), and being the firstborn child, I'm always looking for ways to bring in income for my family, and how I can make our home better. Those are my biggest motivation factors, and that's what enables me to work hard and be disciplined. (Thando)

This group of athletes was particularly accomplished, and they were participants in many world championships, the Olympics, and part of national teams. They were also academically astute, being recognised for academic bursaries. When asked to determine what aided their success, support structures within the university was a huge contributor. In the broader spectrum of human development for persons with disabilities, family support and support from schools were fundamental enabling factors for participation. Intrapersonal factors, such as hard work, discipline, spirituality, and commitment, were also identified as mechanisms that contributed to the success of student athletes with disabilities. While it is promising to hear positive narratives from student athletes with disabilities, there are still areas within university structures that could be improved. These potential areas for improvement are explored next with the intention to bring awareness to the needs of students with disabilities.

## Areas for improvement within the university system

Despite the student athletes with disabilities being so integrally involved in university participation through their own determination and intense support from various divisions, there were still areas for improvement identified by the students. Some of the recommendations for improvement put forward by the students highlight the need for more attention to be paid to accessibility, increased exposure about the achievements of student athletes with disabilities, different modes of communication required for learning, detailed university information for students with disabilities, and training of university staff to accommodate persons with disabilities and socialisation. Narratives pertaining to accessibility included the following:

> I think in terms of accessibility, definitely; maintenance should be improved. Like I said, sometimes the lifts don't work, and that's a problem. (Sipho)
>
> In terms of students with visual impairments, I think that stickers of footprints would work wonders. (Thando)
>
> I think with our residences, I'm very pleased in the way they're modified and adjusted for persons with disabilities and the fact that it's spacious enough for us to move around. But my one problem area is that for people with epilepsy, I think that there should be like a bell that hangs where you can contact protection services immediately if you feel that you're going to have a seizure so that help can come immediately. If you've fallen off your wheelchair, also you can pull that thing so that help can come immediately. Because I feel that as much as I'm in a wheelchair, I'm actually better because there are some who can't use their hands as much as I can. So, if they fall off, then they need someone to pick them up. I think that in terms of safety and maintenance, someone should look into that. (Thando)

In relation to the achievements and socialisation, Sipho felt that more could be done to highlight accomplishments and extend the socialisation of students beyond their sporting groups:

> Yeah, like I wanted to ask why sport for persons with disabilities doesn't get a lot of exposure. There should be more done in making us known.

> Socially, like during the weekends, I don't go out much because there's nothing to do. I'm always stuck in my room and don't have the opportunity to make new friends. I only have my classmates and sporting people. I think the university should have more functions that allow people to come out. A balance between the books and a social life is needed.

When asked about improvements, student athletes advocated the need to ensure that different modes of communication are made more readily available to students with disabilities.

> In terms of people who are deaf, I think much needs to be done because many, if not no one actually, are at this university because there aren't any translators that are hired currently at the university. I think that would go a long way for that type of disability. (Thando)
>
> I also think that a lot has to be done in getting employees, or outsourcing the function of braille transcriptions, because the university currently has one person who does that, and it's not enough, and as a result a person's assignment has to be postponed because there's only one person who's translating these things, and this person is the same assistive device technologist who has to deal with us, so you can't have one person performing all these functions. (Thando)

Thando also identified the need for detailed information for students with disabilities concerning possible restrictions at university as an area for improvement:

> The university should also inform the students when they are at those career days that students must have their own caregiver if they need one. Students must explain all their restrictions to make [sure] the university is aware before you enrol so that measures can be put in place before you come. We had a case of someone who had muscular dystrophy and had to sleep on their wheelchair for the first few weeks because she could not get herself off the wheelchair and take herself to the bathroom and all those things. It took some time for her to confide in us as friends because we were all new at the time. So, when she did, we went to [the counselling services] and she got a caregiver and the university helped her get a bursary to fund the caregiver expenses.

Lastly, training of university staff was highlighted as a problem area for improvement. Thando relayed the following experiences:

> I also think that with tutors and students, during their training, they need to be made aware that there will be students with disabilities in their classes and at their departments. They should know that they shouldn't treat them differently, because sometimes you find that you could get someone with a speech problem is totally shut out of the class because the tutor doesn't know how to handle them, so I recommend that kind of training.

> And, also, in my class particularly, I have a tutor class, and I sit right at the top, and I can't go down the stairs to the front. So, they always say, 'can you guys please come to the front', and I'm left up there alone. So, I think they should be sort of made aware that they need to be considerate. We're not saying they should treat us differently, but they should approach and ask, or we should be comfortable to approach and express our problem.

The university included in this investigation must be commended for the various support systems provided for students with disabilities. While the institution is indeed recognised for their investments in facilitating the inclusion of students with disabilities, there are still areas for improvement identified by participants of this study. The findings of this chapter therefore highlight the complexities in tertiary education experienced by students with disabilities, but also point to resources necessary for successful integration of students with disabilities into higher education.

## Conclusion

For students with disabilities who enter higher education institutions, additional resources are required for full participation in university life, thus expanding their human agency and freedoms (Sen 1999; Tugli et al. 2013)millions of people living in the Third World are still unfree. Even if they are not technically slaves, they are denied elementary freedom and remain imprisoned in one way or another by economic poverty, social deprivation, political tyranny or cultural authoritarianism.","ISBN":"978-0-19-829758-1","language":"en","author":[{"family":"Sen","given":"A.K."}],"issued":{"date-parts":[["1999"]]}}},{"id":183,"uris":["http://zotero.org/users/159279/items/3KJ66S7N"],"uri":["http://zotero.org/users/159279/items/3KJ66S7N"],"itemData":{"id":183,"type":"article-journal","title":"Perceptions of students with disabilities concerning access and support in the learning environment of a rural-based university","container-title":"African Journal for Physical, Health Education, Recreation and Dance","page":"356-364","volume":"Supplement 1:2","source":"uir.unisa.ac.za","abstract":"Disability is an inevitable human phenomenon that limits equitable access as a result of activity limitation and participation restriction in society. For students with disabilities in tertiary educational institutions, lack of necessary access and support services can render them socially and academically excluded and overly dependent. The study assessed the perceptions of students with disabilities concerning access and support in the learning environment of the University of Venda. A self-administered questionnaires were used to collect data from 67 students with disabilities (mean age=26.6±4.7 years. In this chapter, we chose to interview a group of student athletes with physical disabilities who attended a Johannesburg-based university to understand their experiences.

The findings of the chapter, although limited in its generalisability beyond the group of student athletes interviewed, yield important findings regarding enabling factors and challenges faced within the university environment.

When providing insight into enabling factors in the university environment, students identified their own internal desire to succeed, family support and support in their time at school as central to enabling them to be given the opportunity to access university education. These findings resonate with the research conducted by Mutanga (2015) who describes how familial support and positive experiences at school can prepare students with disabilities for tertiary education.

The current study also highlighted that within the university itself, the academic, emotional and recreational (sport-related) support provided, in addition to their personal support structures, were fundamental to successful integration into university life. Experts such as educational psychologists and assistive device technologists assisted the students with academic needs. Social workers were integrally involved in taking care of the emotional support needs of students with disabilities, while the co-ordination provided by the sport manager was invaluable in ensuring meaningful participation in sport. Overall, student athletes related positive narratives about their experiences at the university. This finding resonates with the work of Tugli et al. (2013) in rural universities and demonstrates the central role these kinds of support services play for students with disabilities.

However, despite the fact that the university at which the research was undertaken is well-resourced with many avenues of support for students with disabilities, aspects for improvement were identified. For instance, accessibility for students with disabilities remains a barrier. While there are wheelchair ramps and lifts, maintenance of these structures is important, and the use of some lecture venues that only have stairs remains problematic. This finding extends Engelbrecht and Beer's (2014) study to highlight that the need for accessible infrastructure is important, but that proper maintenance is also needed for the infrastructure to aid students with disabilities.

For the athletes in this study, an expression of the need for publicity of their achievements and the ability to attend larger numbers of social events were identified. This is a novel finding, since the research to date on students with disabilities has only reported on sport resulting in feelings of empowerment and integration (Swartz et al. 2016). From this research, however, the need to make the achievements of students with disabilities more visible was expressed so that their achievements can be publicised in the way that other sporting activities are celebrated.

In terms of academic support, while some support was present for the conversion of material into alternate modes of communication, such as braille, this service is limited to one employee for the entire university. The lack of capacity was therefore viewed as a restraint within the university, followed by the request for more translation resources within the university to be made available. The lack of capacity to aid with alternate modes of communication, however, seems to be a common problem at South African universities, as is reflected by studies in KwaZulu-Natal and Pretoria (Buthelezi 2014; Engelbrecht and Beer 2014).

An additional area for improvement is in relation to attaining detailed university information on career days that could enable students with disabilities to identify factors that could potentially restrict their participation. Herein the students interviewed identified that this kind of information should be requested by students themselves. However, it is also important for university staff to acquire this knowledge so that they can aid students. Staff training, as in other research findings (Ramakuela and Maluleke 2011), also emerges consistently as an area for improvement across South African universities.

From a theoretical standpoint, the benefit of using the capability lens in this research is that it enabled the identification of multiple dimensions that assist or restrict students with disabilities at university. We see that there are enabling factors that can expand the capabilities of student athletes with disabilities in relation to family support and the resilience of students. Learning how this group of students was supported through university structures also highlights the importance of policies in all universities to facilitate inclusion. Following on from the policies, practical implementation from various divisions within the university is also crucial. While the university involved in this research was well resourced compared to other South African universities, the student athletes still identified areas where the institution could improve. From a research and development perspective, these findings speak to the need to monitor and evaluate the services aimed at supporting students with disabilities. These activities are important when considering ways in which to expand the capabilities and promote social justice of students with disabilities in South African higher education institutions.

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# CHAPTER 8

## EXPERIENCES OF STUDENTS WITH DISABILITIES OF THEIR OBSTACLES TO THROUGHPUT IN PROFESSIONAL DEGREES IN SOUTH AFRICAN HIGHER LEARNING: A DE-COLONIAL PERSPECTIVE

Sibonokuhle Ndlovu

### Abstract

Low throughput rates, especially among first year students from lower socioeconomic backgrounds, is one of the challenges that most South African higher education institutions (HEIs) have been struggling with since the transition to democracy. Much of the research aimed at addressing this challenge, however, has focused on women and black students with less attention paid to students with disabilities. In an attempt to gain an in-depth understanding of obstacles to throughput among students with disabilities in South African HEIs, Sibonokuhle Ndlovu conducted qualitative interviews with 12 final year students with disabilities studying for professional degree in the fields of medicine, law, and education. The obstacles to their success reported by participants included inaccessible built environments, unavailability of adapted transport, non-inclusive teaching practices, negative attitudes of the non-disabled university community, and inadequate funding. This chapter describes how underprepared universities are to support, for example, the learning needs of deaf students in comparison to their experience at special schools. Other issues addressed in the chapter include concerns over the shortage of sign language interpreters, and lecturers who are unwilling to use inclusive teaching practices and to provide relevant tailored reasonable accommodations for students with disabilities. Students with disabilities face unique obstacles which hinder their participation with success in professional learning. These are exacerbated by the under-preparedness of institutions to promote inclusive learning environments in which students with disabilities

can thrive. Close consultation with students with disabilities themselves is required to formulate viable measures to make professional learning in higher education accessible for students with disabilities as well.

## Introduction

With the end of apartheid in South Africa, goals were set for the inclusion of formerly disadvantaged persons, including those with disabilities, in professional employment. However, Ramutloa's (2010) study, which was commissioned to explore employment equity in the years 2009 and 2010, reveals that only 3909 people with disabilities were in professional employment in that period. It is of utmost importance to understand the underlying causes of this low number. Based on Earlie's (2008) argument that it is in institutions of higher learning where the output of professional skills is obtained, I considered it important to explore throughput for students with disabilities at a previously advantaged institution of higher learning. While there has been some level of transformation of South African institutions of higher learning and attempts to embrace diversity in student bodies and promote institutional cultures that embrace difference, challenges remain.

Studies on throughput have been conducted previously with the historically disadvantaged social groups, such as women and black students in the South African context of higher education. There is, however, limited work on students with disabilities' throughput in professional degrees broadly, and specifically for medicine, education, and law. It is against this background that this particular chapter is unique, as it sets out to understand obstacles to throughput for students with disabilities. The study is situated at an institution which is said to have good disability support, with a Disability Unit that won an award from the Department of Higher Education in 2012.

De-colonial theory is deployed as a lens through which the obstacles to throughput faced by students with disabilities studying different professional degrees can be analysed. I found this theory helpful to understand the underlying causes of the obstacles hindering the throughput of these students as well as providing a mechanism for conscientisation and raising awareness of this form of oppression. As Dastile (2016) argues, the theory allows the marginalised to 'tell their own stories' from lived experiences, instead of those without disabilities speaking for those with disabilities, which results in misrepresentation and distortions.

Twelve students with disabilities studying professional degrees at final levels (meant to complete their respective programmes in 2014, and graduate into the respective professions in 2015) participated in the study, of which two in medicine, four in law, and six in education. These programmes were selected because they are in the category considered scarce and critical skills by the Department of Labour (DoL, 2005). Though the impairments of the students will be referred to in passing in the chapter, it is not the intention to describe the students' impairments because the chapter subscribes to the 'person first view' (Devlin and Potheir 2006), which means that they are regarded as the same as all other students who are only diverse in their own way. Impairments is therefore not regarded as of any importance.

## Methodology

Qualitative interviews were used to collect data. Data were then analysed in a thematic way (Creswell 2008). At different levels of analysis, similar responses were aggregated and collapsed into minor, and later abstracted into major, themes (Braun and Clarke 2006; Miles and Huberman 1994). Constant comparative analysis, as referred to by Ndlovu (2014), was used extensively to cross check data, and assisted in identifying contradictions and consistencies in the data. The process was important taking in consideration that students with disabilities are not a homogeneous social group, and their different responses could have been influenced by different factors, such as schooling backgrounds, race, economic class, gender, and/or disability categories. Triangulation (Carter et al. 2014) was also used to validate data from the particular students. Major themes that emerged as obstacles to timeous throughput were infrastructure (physical structures and transport), attitudes, funding, and limitations in terms of teaching and learning. The focus of this particular chapter, however, is on the question of delayed throughput resulting from the pedagogical approach towards knowledge acquisition at the institution, and the actual application of theory when practicing at a work setting for integrated learning (which are workplaces where students do their practice). The chapter therefore seeks to address the question: How are obstacles confronted by students with disabilities in professional learning impacting on their throughput at an institution of higher education in South Africa?

## Ethical considerations

Being aware of the vulnerability of students with disabilities, ethical procedures were strictly followed. The author applied for ethical clearance and an ethical clearance letter was provided (clearance number 2013CE106D). Furthermore, permission to conduct the study was obtained from the institution of higher education. The purpose and aim of the study were explained to the participants as a way of obtaining informed consent. They were also made aware that their participation was voluntary, and it was their right to withdraw from the study should they not want to continue.

## Professional learning

For students with and without disabilities to be professionalised—to complete the specific programmes they are studying and meet the requirements within the minimum time-frame—they should have full access to professional learning. This involves the acquisition of the professional knowledge of the specific professional degree, as well as the ability to apply it in field-practice. It is important to state that professional learning is a process and should not be rigidly understood as one that ends at graduation. It is a life-long process in an individual's professional career, and it continues as professional development even after one graduates into a profession. Before graduation, it involves teaching and learning of professional knowledge (theoretical and practical) both at an institution of higher learning and at a site of work for integrated learning, where theoretical knowledge is applied in practice. I argue that this culminates in professionalisation of students with and without disabilities studying professional degrees. In this chapter, I discuss obstacles that hinder students with disabilities from accessing professional learning, which then delays their throughput.

## Throughput

Throughput is defined broadly by the Council of Higher Education (CHE) (2007, iii) as: ‘The calculation of how many students in a given cohort completed their degree and graduated within the stipulated time, how many dropped out and how many took longer than the stipulated time to graduate’.

This suggests that the throughput rate is not only about those who complete their degrees within the stipulated time, but it includes those who drop out and those who complete later than others. Some higher learning institutions calculate it by matching the graduation rate of a cohort of students against the year of enrolment and completion for specific programmes. Thus, a throughput rate can be calculated in different ways in different learning contexts and as there are different understandings of it. For purposes of this chapter, I understand throughput to mean the rate at which students (with and without disabilities) prove themselves able to do the amount of work required for a specific programme and who are therefore able to complete their programme within the allocated minimum time-frame. Simply put, it is the ‘completion of the programme timeously’. Thus, I am specifically interested in whether or not students with disabilities who were supposed to complete their medicine, law, and education programmes in 2014 were able to meet the requirements for their specific programmes within the minimum time allocated at a specific university, and what their experiences were in this regard.

## Delayed completion of programmes

Students with disabilities across the three programmes do not complete their study within the minimum stipulated time. It should be noted that only students who had already reached a relatively advanced level of their studies were interviewed in all the three programmes. There could be many more who might have dropped out even before they got to their final year.

Table 1: Completion of study across the three programmes

| School | To complete | Completed | Not completed |
|---|---|---|---|
| Medicine | 2 | 1 | unknown |
| Law | 4 | 0 | 4 |
| Education | 6 | 0 | 6 |
| Total | 12 | 1 | 10 |

Table 1 shows that all students in law and education who were expected to have completed their study in 2014 and failed to do so. One medical student completed his study in that year, and another's completion is unknown, as he did not respond to the follow-up requests.

## Professional learning of medicine

The two participants stated that they are included in their programme's professional learning that lecturers cater for their unique needs, and this ensures that they have full access to professional learning. When special provisions and access arrangements are made for them, this enables them to have the same learning opportunities as other medical students. Examples of accommodations made for them include that their lecturers provide them with instructional and assessment assistance.

> The Department considers me in learning because I told them of my problem before the start of the block. In every examination I write, I have an extra time of thirty minutes, thirty minutes of every hour. They also print the exam on large print and give me my room to write from. This helps me a lot in terms of my eyesight. (Medical student, 1)
>
> A disabled student has other issues of access to overcome. When my lecturers got to know that I can't hear, they made sure I got all the important stuff for my learning. They gave me notes prior to the semester, and they told me I had no choice but to gather up myself and do my work. They do not give me special treatment, but they assist me to access the medical information, (Medical student, 2)

What I drew from these statements is that when it is known that a student has a specific limitation, there is an intervention that enables the unique limitation to be overcome. It seems that the access arrangements for examinations and the provision of notes in advance enable both students to access the medical knowledge. Thus, each student's perception is that he is catered for in a way that helps his professional learning.

## Practical learning in the workplace

The two students also said that they are included at the site of work for integrated learning that teaches students to apply theory to practice. They do their field practice alongside other medical students, and their unique needs are also catered for in this setting. For example, they are given extra time to complete tasks. The students say what helps them most is that their lecturers always explain to them what they can expect to find in hospitals, and what tactics have worked for other students with disabilities. This enables them to prepare themselves so that they have solutions for the problems they encounter at the place of work. Describing their practical learning, they said:

> It’s actually a connected kind of a thing. When you go to practice in the hospital you are already exposed to the conditions that are very similar to what you have been learning. I am able to use that knowledge and that information myself in the field because in Medicine you learn as you practise. The Medical School is doing so well in preparing us for the profession. Honestly, I don’t see how they can improve. We are taught the medical skills as all other students. (Medical student, 1)

> We are taught like all other students when taught the medical skills and everything. There is special attention when we do those things of extra time. We do practise well in hospitals and all the stuff. (Medical student, 2)

The above extracts reflect the two participants’ perception that the accommodation and support they receive enables them to surmount any obstacles faced during professional learning, both at university and in hospitals. Learning to apply the knowledge, according to these students, starts at the institution. They see their ability to apply their knowledge hospital setting as being a result of the fact that they are prepared for the conditions of field practice by the academic staff at the institution. This preparation makes it possible for them do their field-practice well.

## Throughput in Medicine

Both students with disabilities studying Medicine stated that they expected to complete their programme within the minimum stipulated time. The first student stated that: ’I know I have to finish next year, I have to graduate’. The second one also stated:

> The university has not put a barrier for me to complete the programme. In the medical field, this university has enough support for students with disabilities to go through in time and the most important thing in medicine is management of time. (Medical student, 2)

To establish whether the students with disabilities completed their programmes within the minimum time, I contacted them after they ought to have graduated. One did not respond, while the other participant had completed his programme within the minimum time as he had predicted, had graduated with distinction, and gone on to do his PhD at another university. This participant had previously completed his undergraduate study within the minimum time of six years for medicine, and had passed well with a final mark of 74 per cent. The student then also passed his postgraduate study within the minimum time, and obtained a distinction. Clearly, this particular student is exceptional. There is no doubt that regardless of the setting or obstacles faced, exceptional individuals are able to succeed. It could be the reason why one student in the programme of medicine felt that he had not confronted obstacles with respect to professional learning. I argue, however, that opportunities for success should not be limited to the privileged or exceptional few who have material or personal resources that make it possible for them to thrive regardless of circumstances.

Medicine is categorised as a powerful degree programme (Haralambos and Holborn 1991) and is prohibitively expensive. It has been argued that due to coloniality of knowledge, there are programmes (disciplines) that are considered more powerful than others in terms of scientific knowledge (Ndlovu 2016). I view Medicine as one of these programmes, and I argue that powerful programmes are for the powerful. This further suggests that only those from an economically relatively privileged background and from elite schools have the opportunity to access the programme at a previously advantaged institution of higher learning. As Santos (2007) explains, within the zones of location, elite universities are in the zone of being. That being the case, it could be that the two students with disabilities mentioned have access to professional learning because they come from elite backgrounds, and it is by virtue of their relative privilege that they are not hindered from accessing professional learning in the particular programme, and are able to navigate the obstacles they encounter successfully.

Despite both students reporting an overall positive perception of their experience of applying the medical theory learned at university to practice in a hospital setting, there were also moments when contradictory experiences were mentioned. One noted that students with disabilities are not readily accepted by patients and other staff members in hospitals and this that makes the field-practice, which is part of professional learning, difficult:

> You have this fear when you go there, how are they going to treat me? Are the patients going to accept me? The university system is inclusive but when you go outside into hospitals, there is none of that sort. (Medical student, 2)

Students studying in privileged environments, and/or who come from privileged economic circumstances, must still negotiate the negative attitudes that society can have towards those with disabilities. Coloniality of being, part of de-colonial theory, enables us to explain this as it reveals how the notion of ‘the other’ has emerged. Ndlovu-Gatsheni (2001) maintains that through using normalcy as the standard measure, difference, plurality, and multiplicity are denied. Specifically, those with disabilities are socially constructed as ‘the other’—as other to the supposed norm. This is a result of the social ordering which uses a ‘normal body and mind’ as a standard, and all individuals with different bodies and minds are viewed as deviating from the norm, and are hence labelled ‘disabled’ (Quijano 2000). By virtue of such a label, the ‘normal’ society discriminates against such people and manifests negative attitudes towards them.

## Completing law at the institution

Students with disabilities in the programme of law have limited access to professional learning and tend not to complete the programme within the minimum time. They confront obstacles that interfere with their learning, both at the institution and at work settings for integrated learning, and this contributes to them failing courses and having to repeat years and becoming overloaded. As one participant commented, ‘a lot of us are failing and we end up staying here even longer than other students’. And another said:

> It’s extremely difficult for you to pass. It’s exceptionally hard. You will have many courses left over again for the next year, and then the next year, and then the next

> year, so you end up being here for years, and you drop out because struggling will discourage you. (Law student, 4)

When follow up was made, none of the fourth-year law students I interviewed who should have graduated in 2015 had graduated yet. Thus, though students with disabilities can complete the law programme, they take longer than others. Some of them do not complete at all, but drop out of the programme entirely. The participants studying law reported feeling excluded from learning in the law programme although their accounts suggest that there are pockets of individual accommodation facilitating their learning. Isolated incidences of lecturers showing concern for students with disabilities and making efforts to include them in their teaching were mentioned. Though they did not specify the numbers, the law students stated that there are only a few lecturers who are willing to make an effort to include them, and that many are not:

> I heard one lecturer mentioning people with sight issues when she was putting an overhead projector. She offered help and said such students should come to her office. I realised that there is someone who understands. (Law student, 3)

Thus, some lecturers show an awareness of how certain mediums employed to convey knowledge in the teaching process exclude students with visual limitations from learning. These lecturers make arrangements to help those students to access learning. However, what the students describe suggests that it is left to the discretion of individual academic staff whether or not to include those with disabilities, and that only a few do so. Students with disabilities confront obstacles which are difficult to overcome, because not all lecturers are willing to make the effort to change their practices.

What this insight points to is the incomplete and partial nature of institutional transformation, with efforts at inclusion often being piecemeal and based on individual will, rather than institutionally and systemically entrenched. As Dastile and Ndlovu-Gatsheni (2013) have argued: that democracy and inclusion are still unfinished business.

Students with disabilities report that most lecturers do not consider their unique learning needs with regard to teaching instruction and assessment. They state that they are limited in their learning by materials that are used in teaching which are inaccessible to them. For example, lecturers use overhead transparencies most of the time, and do not make large-font printouts available to them. In addition, the font in the course packs is also inaccessible and their reading materials are distorted when converted to braille. The cumulative effect of all of this is that they are effectively excluded.

> They will tell you, ‘we have a lot of work to do. As lecturers we are expected to be studying, we are expected to mark; we are expected to do this and that. So what you are asking for might be a lot too much. (Law student, 1)

The concept of Universal Design (Centre for Universal Design, 1997, 2002) references the idea of designing education in such a way that all students in their diversities are included from the outset. When the differences and plurality of all students is not taken into consideration, education is designed from the standpoint of what is viewed as the norm and inclusion of those with disabilities is seen as optional, and as extra work, rather than being an inherent requirement. As with many other professional degrees, law students are aware that field practice is critical. While they are taught a lot of theoretical knowledge at university, they have very little time to apply their knowledge in practice:

> There is a lot of theory without knowing to apply it. When you are just a student in class and you are just taught the principles, you struggle to see how those principles apply in court scenes. (Law student, 2)

Another one also confirmed the difficulty:

> We are not prepared to deal with people but to deal with papers. Law is greater than theory. Yes they just give us theory. (Law student, 4)

It has long been acknowledged (see for example Nicholson 2004; Motala 1996), that at law schools in South Africa, learning involves students going to class and taking lecture notes from volumes of content knowledge that consist of statutes, case laws, legal arguments, and argumentative principles, which they are then required to learn and reproduce in tests and examinations—an approach which does little to integrate the theoretical and practical components of legal education. Attempts to overcome this include, for instance, introducing clinical legal education which emphasises practical learning into the law curriculum (Letsika 2002). However, the students' perception is that professional learning in law is still limited in terms of practical learning. Their perception is that this is a result of academic staff who value teaching theory more than providing opportunities to apply the principles of law in field practice:

> My professor, who is teaching me a law of evidence module, was like you get paid for your knowledge and not how you apply it. That's what they are teaching us: just concentrate on acquiring knowledge so that you are able to regurgitate it. (Law student, 3)
>
> They are teaching us that the practical aspect is irrelevant. Whether people are experiencing social or legal problems in society, that's not important. That's not law in its practical sense. (Law student, 1)

Segalo (2016), who writes with specific reference to psychology, argues that there are disciplines guilty of applying imported knowledge without first assessing its relevance to a specific context. Letsika (2002) observes there has been a long-standing complaint in the legal professions in Northern America that institutions of higher learning do not expose students of law to adequate practice in order for them to acquire necessary lawyering skills. The students' experience speaks to a law curriculum resulting from the importation of knowledge and methodologies of teaching and learning without taking the South African context into consideration. While this could negatively affect all students (including those without disabilities) studying law, it might have particular adverse consequences for those with disabilities. Students with disabilities say that what negatively affects other students is compounded for them. One student said:

> Law for a student with a disability is not real enticing here. There are many, many challenges that even a normal student faces, and when it comes to you it’s ten times even worse, because all these things that makes you different are not taken into account. (Law student, 2)

As they apply the theoretical knowledge to practice, the students with disabilities encounter some people at work settings for integrated learning who still hold the view they are not as competitive or competent as those without disabilities in terms of professional (practical) learning. In addition, some people are just not comfortable having them around. Some perceive students with disabilities to be a financial burden.

> It goes back to people’s mind-sets. They never think a disabled student is equally intelligent; is equally a hard worker. They expect that a disabled student always complains and would want sick leave. (Law student, 4)

As professional learning includes both theoretical learning and the ability to apply the learning in practice, when students are confronted with attitudinal barriers that limit their ability to learn in practical settings, their education is undermined.

## Education

Students with disabilities in education are also limited in their access to the professional learning which would allow them to complete the programme timeously. As they relate their experiences in learning, the reasons for this are exclusionary practices of teaching, inaccessible media of teaching and learning, and inequitable practices that persist and inhibit them from applying to integrated learning settings. These students therefore take longer to complete the programme than the minimum stipulated period. To the extent that such students do succeed, their insights suggest that this could be ascribed to individual accommodations at the institution, rather than being the result of entrenched and universalised norms of practice.

In the experience of the participants, a few lecturers are willing to include them in their teaching, and field work is enriching when it takes place either at a special school or accommodative mainstream schools. However, while these can be considered to be providing opportunities for professional learning, these opportunities remain minimal. Thus, as is the case in the other two programmes, it can be concluded that completion of the programme in a timely manner is limited.

When, in the beginning of 2016 a follow-up on the six students who were supposed to have completed their studies in 2014 to graduate in 2015 was made, none had graduated. One of them stated:

> I finished my degree last year [2015]. I had health issues. I fell three times and broke my arm and I also lost my mother who had cancer for four years. I am graduating at the end of the month [2016]. (Education student, 1)

From the student's statement, I read that obstacles to throughput are not only encountered in the classroom and in the field. Like other students, those with disabilities also have personal issues that contribute to delaying their completion of the specific professional programmes they are studying. It may be thought that in the absence of appropriate support, these kinds of obstacles which may be faced by any student, have more acute consequences for students with disabilities.

Similar to the law students, the participants with disabilities studying education related that they are excluded from professional learning, although pockets of individual accommodation do exists, which enable the students' professionalisation to a certain extent. Despite these opportunities, which are the result of individual accommodations, participants cited specific obstacles that limit their professional learning, including the failure of most lecturers to include them in their teaching.

> The lecturers forget us. They would say 'sorry I forgot to send your notes', and all stuff. Even when they are teaching, they forget us, even in tests and in assignments. (Education student, 3)

Some pointed out that certain lecturers do not send their learning materials for conversion in time. Conversion is the process of changing materials to an accessible format for students with visual impairments, such as converting print to braille or large print. As a result, these students are given their assignment topics late, they then submit them late, and receive feedback late. Another obstacle is that the process of converting print to braille often results in distortions and omissions. Lecturers also use overhead transparencies and PowerPoint when teaching, and these exclude students with visual impairments.

The students' perception is that those with disabilities are marginalised by academic staff. De-colonial theory would point to the general organisation of structures in society using 'normalcy' as the standard (Quijano 2000). Based on this, physical and social structures, including practices such as teaching, are all aimed at the 'normal'. It is no wonder that lecturers also organise and design their teaching practice for 'normal' students, and in the process those with disabilities are forgotten and excluded.

The unwillingness reported by our participants of some members of the academic staff to include students with disabilities is consistent with Fuller et al.'s (2004) and Madriaga's (2010) findings. These studies found that in the British context, certain lecturers are unwilling to go out of their way to include students with disabilities. In formerly-advantaged institutions in South Africa, the unwillingness referred to here does not only affect students with disabilities, but includes students from other previously-disadvantaged groups. The Council of Higher Education (2008) views this as one of the internal inefficiencies which impacts negatively on transformation.

Two postgraduate students in education with partial hearing loss, who identified as deaf, shared the experience of the learning of those with hearing impairments. They pointed to the problem of the expense associated with employing interpreters, and that interpreters, as human resources, are not always waiting on them for their learning at the institution:

> Interpreting is a high-cost item because for an interpreter to interpret for an education student, he should be someone who understands the educational language, content, terms, concepts, reading and all stuff that is educational. (Education student, 2)

They report the possibility that these interpreters could be sick, exhausted, and also take leave while they are needed to interpret for students with hearing impairments. The students state that when interpreters are unavailable, they miss lectures because making backup plans for interpretation at short notice is difficult. They also say that interpreters who are not educationists often mistranslate what is taught, and students with hearing impairments therefore write meaningless (and ultimately useless) lecture notes.

The problem of the high cost of interpreters for the deaf as well as the limited availability of those qualified to interpret is widely documented (see for instance FOTIM Report, 2011). Thus, while all students with disabilities face obstacles to inclusion in professional learning, this exclusion is often felt more acutely by those with hearing impairments.

Pointing to the importance of the environment rather than the disability itself in determining levels and forms of exclusion, the education participants—who do their field practice at two types of schools, namely special and mainstream schools—all reported that they felt most included at the special schools where they did their practical application and in some accommodative mainstream schools. They described the special schools including them in terms of material resources, physical accessibility, attitudes, and accessible teaching methods:

> I was accommodated—it was a special school. I was like other teachers. They treated me like one of them. So I asked the TE office that they place me at a special school for third and fourth year. (Education student, 5)

Students with disabilities experience better treatment in special schools and this provides them with better field practice. They therefore often prefer these schools for their teaching experience deployment. Students with disabilities who were interviewed by Chaitaika (2007) in the Zimbabwean higher learning context also stated that they felt a sense of belonging in special schools. From this, she concludes that with special schools still functioning, there is a threat to inclusive education in the mainstream (Chataika, 2007). The perception of students with disabilities is that special schools include them and offer them opportunities for better field practice. A potential result of this is the perpetuation of special education in segregated institutions, because the needs of those with disabilities are (often) met within these contexts and not in mainstream contexts. This feeling of inclusion could make them consider becoming ‘specialist teachers’ for learners with ‘special needs’ in special schools, as was the case in the past (Howell, 2006). As one participant put it, ‘And I realised that ok, I can’t teach in the mainstream’. Another stated:

> I will eventually want to go to Special Needs Teaching myself. I am a Special Needs sort of a student. (Education student, 6)

While special schools are inclusive and allow students with disabilities to do their field practice well, their positive experience could inadvertently result in the perpetuation of segregation on the grounds of disability, defeating the whole idea of inclusive education in mainstream settings as proposed in the policy (DoE 2001b) and South Africa's higher education transformation agenda (CHE 2008). As some participants reported, however, there were some mainstream schools which they experienced as accommodative, and they were able to complete their field practice optimally in these schools. As one student stated: 'There was no time, where I felt, you know what, I had a disability because the infrastructure had always been conducive for me. (Education student, 1).

Another participant added:

> The school had a lot of teaching materials; I had no problems with preparing for the lessons and the mainstream teachers were accommodative; I gained a lot of content and teaching methods. (Education student, 3)

What this points to is that it is possible for mainstream education institutions to accommodate students with disabilities and to provide appropriate learning environments in which these students can feel that it is possible for them to function optimally and succeed. When students with disabilities are placed in mainstream contexts where they are expected to gain practical experience to further their education, but which exclude them, they report that their professional learning within these contexts is limited. Participants spoke of the inaccessibility of such schools to them in terms of their built environment, resources, teaching methods, and negative attitudes from other teachers. They recalled that their field practice in those schools was difficult:

> The focus is still on the mainstream. By the mainstream, I mean the non-disabled. They will talk about chalkboards, charts and so forth. I cannot write on the chalkboard, I cannot design a chart because of my disability. Does that mean I cannot teach? (Education student, 4)

So, despite advocacy for inclusive education in schooling, there are still mainstream schools that exclude those with disabilities. While this student has the capacity to teach like other students, by virtue of the specific context and its lack of accommodations of disability, he is excluded.

When students with disabilities encounter low expectations with regard to their capabilities, they become uncertain as to whether they will be accepted when they go for field-practice. Negative stereotypes about disability persist and the participants understandably expressed distrust of society's professed value of inclusion. Despite policies promoting inclusion, certain work settings for integrated learning are still not transformed to enable all students to access practical learning in all their diversities. Students with disabilities feel comfortable in special schools because they are included and are therefore able to do their field-practice well. However, in my view, that perpetuates segregation and discrimination. To us, those with disabilities feeling comfortable in segregated settings such as special schools defeat the whole idea of inclusion, and, consequently, professional learning in inclusive teaching and learning settings is hindered.

## Conclusion

This chapter reveals that across the three programmes of law, medicine and education, students with disabilities take longer than the required minimum time to complete their study. They confront the same obstacles as others without disabilities, and encounter others specific to them. De-colonial theory enables us to understand that while persons in the non-West are oppressed, persons with disabilities confront several layers of oppression. Those with disabilities experience the same obstacles as other oppressed students. However, theirs are exacerbated and compounded by the unique needs resulting from their different impairments, hence their delayed throughput. I acknowledge that there are still internal inefficiencies in previously advantaged institutions of higher learning that hinder transformation, and that the formerly disadvantaged students without disabilities also confront obstacles that hinder full access to professional learning. However, those with disabilities face a doubled plight, because, among other things, they require specific teaching and learning media for them to access learning. According to their experiences, this is not always available to them. It should also not be overlooked that students with the same impairments could have different obstacles and their throughput could be delayed differently. I conclude that, across the three professional programmes, students with disabilities themselves whose experiences make them the experts regarding the obstacles they confront in their professional learning that delay their throughput, should be the ones that offer recommendations for how to intervene and improve their learning at the institution and enhance their opportunities to succeed and complete their training in the minimum prescribed time.

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# CHAPTER 9

## HEALTH PROMOTION AND INCLUSIVE EDUCATION IN HIGHER EDUCATION INSTITUTION SETTINGS

Tshifhiwa Ignetia Mashau

### Abstract

One aspect of inclusion in which most universities, including those in South Africa, continue to lag behind, is the promotion of the health of students with disabilities. In this chapter, Tshifhiwa Mashau investigates the factors which hinder health promotion for students with disabilities at South African higher education institutions (HEIs). This chapter discusses how the exclusion of students with disabilities from health promotion initiatives can be attributed to various reasons, which range from some HEIs not having any health promotion and inclusive education policies at all, to those which have them, but do not implement them effectively because of a lack of knowledge and understanding of how to do so. This chapter highlights university leadership's—particularly top management's—lack of being proactive when it comes to ensuring that health promotion policies are put into practice. Health promotion and inclusive education for students with disabilities continue to be hindered by misunderstanding on the part of many HEIs which address disability in medical terms, instead of focusing on health promotion in order to support the health needs of students with disabilities better. The chapter argues that HEIs need to take the health promotion of students with disabilities seriously if these institutions are to create inclusive higher education environments where all can thrive both academically and socially.

### Introduction

Through policies and practice higher education institutions (HEIs) in South Africa have been striving to promote the health of all students as well as reducing barriers to learning

(Mutanga 2017). However, the ideals of health promotion and inclusive education policies and practices are still not well aligned with students' experiences. According to Mafa (2012), HEIs are moving towards the realisation of inclusive education. Efforts by South African HEIs to transform the lives of students with disabilities remain hindered because of the gap between policy and practice, with the experiences of students with disabilities often pushed to the margins, with a tendency to focus more on their inability, rather than their voices and abilities (Disabled People of South Africa 2001).

The reported experiences of students with disabilities range from encountering negative attitudes, misconceptions about their disabilities, and environments and health services that do not cater adequately or specifically to their varied needs (Mutanga 2017). The health promotion model and settings theory can help to shed light on how to find strategies to support these students better. This chapter argues that an institution needs to be promoting the health of its students before it can be inclusive in its policies, as stated by Landsberg et al (2019). Discussions about students' experiences can only be fruitful if institutions are eager to understand and value the experiences of their students, and to understand that education is a basic right, and not a privilege (Disabled people of South Africa 2001). It cannot be denied to anyone, irrespective of their disability.

According to De Roos (1977; see also Mutanga 2017), an HEI is a setting where knowledge and skills should be taught, and where the social and physical environment should be created to empower students. Health promotion and inclusive education constitute a paradigm rooted in the concept of human rights and a social model that bridges equality and equity (Jonsson 2001; Donald et al. 2010). The argument is that effective education is only possible when students can participate fully in order to benefit from that education. Instead of merely addressing illness and disabilities, HEIs need to prioritise health promotion and inclusive education across the institution to maximise the participation of students with disabilities.

## Conceptual framework

### Inclusive education

Health promotion and the settings-based approach to inclusive education for students with disabilities are not well established within student support services in HEIs in South Africa. Both the concepts of health promotion and inclusive education emphasise the rights of students and the imperative of transforming the system of education to accommodate students from diverse backgrounds irrespective of their disability. Despite the efforts to develop these concepts and practices in HEIs, the experience of students with disabilities is that their needs are not well understood (Mutanga 2017).

While many HEIs have done much to change the physical environment and outlook of their institutions in terms of lifts and ramps and the like, when it comes to other forms of support, they still do not allow students with disabilities to participate fully in the system (UNICEF 2013). The mistake which has been made thus far in the South African higher education context is that policies and initiatives are often designed without input of students with disabilities (Mutanga and Walker 2017).

## Health promotion

Both health promotion and inclusive education herald a shift from a focus on physical health and students' disabilities to the institution's social environment and practices. These approaches signal a shift from the deficit model—focusing on what students with disabilities lack—to the social model which calls for the removal of barriers to learning and empowerment of students with disabilities in HEIs (Mutanga and Walker 2015). Their empowerment though could only be strengthened if they are fully participating in the institution's programmes. Similarly, understandings of health promotion have been dominated by medicalised discourses (Mutanga 2017) where disability is seen in terms of curing or preventing a disease or releasing a barrier, hence experiences and particularities as well as strengths and abilities of students with disabilities remain only partially attended to.

## Settings-based approach

The settings-based approach to health promotion has its roots in the World Health Organisation (WHO 1991; Dooris 1998) and the Ottawa Charter for Health Promotion (WHO 1986). The settings-based approach has drawn its strength from salutogenic research which defines health socio-ecologically, and as something that can be developed outside the health sector (Dooris 2009). The Ottawa Health Charter identified that: 'Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love'. (WHO, Ottawa Charter for Health Promotion 1986; see also Bloch et al. 2014). Furthermore, as noted by the WHO (1986) 'health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members'.

This approach therefore focuses on the creation of environments which support health, developing personal skills, and the reorientation of health services to shift away from focusing on individuals and their disabilities towards focusing on the environments and settings—such as schools and universities—in which those individuals are or are not able to function optimally. In fact, the environment must be enabling for students to learn (Mashau 2019). This approach fits well with the doctrine of inclusive education, which according to Dooris (2001), focuses on the elimination of barriers created by society that prevent people with differences from enjoying their human rights on an equal basis with others (Mutanga and Walker 2017)—particularly with regard to education and economic empowerment.

The settings-based approach acknowledges that for people to learn, work, and live, their environment needs to be adapted to suit to their disability, and they need to be empowered as well. The settings-based approach is based on the following principles, as stated by Scriven and Stiddard (2003 see also Scriven and Hodgins 2012):

- A holistic, socio-ecological understanding of health;
- A focus on populations, policy and environments (physical and social);
- Social justice and equity;
- Sustainability;
- Community involvement;
- Empowerment; teamwork;
- Agreement and mediation;
- Advocacy ;
- Settings as social systems; and
- Settings as part of an interdependent ecosystem.

Mostly in HEIs, health promotion and inclusive education policies operate in isolation (Mutanga 2017; Mhona, 2018), and in some institutions health promotion is entirely absent as a basis for policy or practice. In a true sense, these two policies need to work closely together—one cannot operate without the other. Students with disabilities are discriminated against when health promotion and inclusive education are seen in isolation and students with disabilities are treated as a separate category of students (Lyner-Cleophas et al. 2014). Moreover, the specificity of the needs of these students is sometimes overlooked and students with disabilities are lumped together in a single category.

In the argument by Deliwe (2016) it has clearly been articulated that disability is diverse in nature, and how students need to be supported differs. It is crucial, therefore, to have facilities to cater for different disabilities, for instance, in relation to classroom design and lecturer approaches. It is unfortunate that most staff are not trained to teach students with disabilities (Mutanga 2017), such as blindness, physical impairment, deafness, muteness as well as those with cerebral palsy—each of which calls on the setting, including lecturers, to modify practices (including for example design, lighting, assistive device availability) and approaches to learning (Schmidt and Cagran 2008).

The experiences of students with disabilities are often expressed in terms of access, even though it can include issues of curriculum, teaching and learning, as well as assessment (Mutanga 2017; Matshedisho 2007). The study done by Fuller et al. (2004) indicated in the lecture hall, students experience lecturers fast rate in speech, difficulty in participating in discussions, and other engagements with fellow students which impact negatively on their success and sense of inclusion. The notion where deaf/hard of hearing and visually impaired students cannot record lectures as well as not being able to access the lecture halls undermine the goal of students entering the institution to increase their knowledge to develop their skills. With regard to students with disabilities who use wheelchairs to reach the lecture rooms, the inaccessibility of buildings denies the full integration of these students in the life of the university (Mutanga 2017); above all, to obtain a qualification which will improve their lives and put them in a position to be able to optimise control over their own health.

Policies underpinning HEIs' approaches to disability in South Africa's disability matters have been on the agenda of many countries, as well as the HEIs in South Africa. Policies which support students with disabilities in South Africa include: The Constitution of the Republic of South Africa (1996). In the Constitution, people with disability are taken into consideration. For example: everyone is equal before the law, and has the right to equal protection under, and benefit of, the law. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative—and other measures designed to protect or advance persons or categories of persons disadvantaged by unfair discrimination may be taken.

## Education White Paper 6

In its explanation of inclusion, the Education White Paper 6 (2001) defines inclusion as the acknowledgement that all children and youth can learn, and that they need support. Again, inclusive education enables education structures, systems, and learning methodologies to meet the needs of all learners. It further stipulates the acknowledgement and respect for differences seen in learners, whether due to age, gender, ethnicity, language, class, disability, HIV, or other infectious diseases.

To meet the needs of all learners there must be changes in attitude, behaviour, teaching methods, curricula, and environments (Mutanga 2017). The participation of all learners needs to be maximised in the culture and the curriculum of educational institutions and barriers to learning uncovered and minimised (Education White Paper 6, 2001).

## White Paper on the Rights of Persons with Disabilities

The White Paper on the Rights of Persons with Disabilities (2016) calls for the inclusion of people with disabilities in society, and calls on government, civil society, as well as the private sector to work in collaboration to ensure their socioeconomic inclusion. This is done to create a caring environment which creates a society where people with disabilities enjoy the same rights as their fellow citizens. Institutions such as HEIs need to share equal responsibility of taking care for their students. The provision of the White Paper on the Rights of Persons with Disabilities (2016) is to accelerate transformation and redress with regard to full inclusion, integration, and equality for persons with disabilities. This White Paper (2016) aims to accelerate the implementation of existing legislation that advocates equality for persons with disabilities, removal of discriminatory barriers to access and participation, as well as to recognise the right to self-representation. However, the challenge is that the White Paper does not offer clear implementation strategies of inclusive education in the tertiary education context (Tyobeka 2006).

## Higher education institutional policies

The higher education institutional policies may differ however, as per suggestion by the 4A Framework which suggest that inclusive education systems need to be available, accessible, acceptable, and adaptable (Ramaahlo et al. 2018).

Higher education institutions, by nature, should have disability policies in place where they attempt to reach out to their students in one way or the other (Mutanga 2017). The University of KwaZulu-Natal (UKZN 2004), in its policy documentation, stated that it will provide adaptive and assistive technology to cater for students with disabilities. The University of Johannesburg (UJ) is committed to minimise barriers to learning, however, its admission of students with disabilities is subject to the admission requirements of the university (UJ 2015), whereas Stellenbosch University Disability Access policy is aligned to its strategic vision as it envisages a transforming university that promotes the interests of diverse people on its campus (Stellenbosch University 2018). Despite the shortfalls by higher education institutions in South Africa, the country itself is committed to an inclusive education system that does not discriminate against students with disabilities, because university policies mostly translate the imperatives of the United Nations Convention on the Rights of Persons with Disabilities into institutional mandates that oversee the implementation of inclusive education (Ramaahlo et al. 2018).

In most cases, these policies' approaches to disability is shaped by the medical model where the problem is located within the students, and can only be solved through medical intervention and support structures established to support students with disabilities. However, within the same policies students are excluded, since their services can be rendered within the particular unit of an institution instead of the whole institution (Mutanga 2017). One such example is the University of South Africa, where the directorate of Advocacy and Resource Centre for Students with Disabilities (ARCSWiD 2019) attend to the needs of students with disabilities. In addition, the same institutions tend to ignore students with disabilities' participation in decision making.

In the practical provision of resources for students with disabilities there is a serious mismatch between the needs of students with disabilities and the provision of resources in various institutions (Mashau 2015; Mutanga 2017). When they pass Grade 12, many students with disabilities have to move to other provinces to further their education, because institutions in their vicinity do not cater adequately for them (Scriven and Hodgins 2012).

## The range of disabilities

The definition of disability has not been the easiest one to define. Mutanga (2013) indicates that it is a contested identity because it has always been defined based on a physical ability an individual has. Because of poor understanding throughout history, it has led to misconceptions and the perpetuation of exclusionary practices (Swart and Pettipher 2005). Given the definition of disabilities by Machailakis (2003), disability has to do with the attitude of people around the person who is regarded as being disabled. However, a definition by Shakespeare (2013) presents disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical limitations, and thus excludes them from participation in the mainstream of social activities. Therefore, for the purpose of this chapter, this definition of disability will be used to define students with disabilities, since they face a wide range of inconsistencies in terms of support which interfere with their learning. The general disabilities that many students live with, are outlined below.

## Visually impaired

Visual impairment refers to people who have lost sight to a limited degree, and that cannot be rectified by eyeglasses. In addition to the definition, such visually impaired people squint, and they also need a distinct light to see clearly. At some point, they have blurred vision (Howell and Lazarus 2003). Visual impairment can also explain people who are totally blind to an extent that there is a total loss of eyesight, although they could have a perception of light (Landsberg et al. 2019).

This kind of disability includes students who have difficulty in seeing, either mildly or severely. These students experience learning difficulties in terms of learning and teaching study materials which might not be user friendly (Seyama et al. 2014). There are students who are partially sighted, and those who need to be guided either by helpers or guide dogs, and those who are totally blind whose study material is printed in braille. These students experience difficulties (Howell and Lazarus 2003) even before they study at a higher education institution, because the information on the internet about the institution is not available in braille. Seyama et al. (2014) pointed out that the availability of information is not adequate—notably, it must be accessible. Apparently, these students are excluded before they are enrolled. If they do manage to enrol, their studies will be very strenuous throughout with many institutions effectively excluding them from full participation, regardless of policy.

## Hearing impairment

Hearing impairment is defined as the sensory impairment of not being able to hear, and usually brings to mind the need for an amplification device, speech therapy, and often the assumptions that signing and gestures can always be used as a means of communication (Landsberg et al. 2019). Most students who are hard of hearing experience difficulty (Scriven and Stiddad 2003), especially those who are registered at contact HEIs where they have to attend lectures during the day. Many institutions have less than three sign language interpreters to cater for students who have difficulty in hearing. Sign language, like any other language, has different signs for different meanings.

## Communication disability

Disability in communication refers to the limitation in the ability to receive, send, process, and understand verbal, nonverbal, as well as the graphic symbol systems (American Speech- Language Hearing Association 1993). Furthermore, people with communication disability may experience challenges because of both the impairment and the social and environmental barriers that hinder them from participation. Not everybody can communicate fluently. To start with, there are students who have speech impediments, and some are unable to communicate. There are those students who have been the victims of attending disadvantaged schools where code switching was common. That is the alternating use of languages of teaching and learning in English where educators switch between mother tongue and English (Clegg and Afitska 2011). Hence the introduction of literacy courses in higher education institution to bridge the gap of communication is a widespread need.

## Physical disabilities

According to Landsberg et al. (2019), physical disabilities refer to the impairments of the skeleton and muscle systems. Furthermore, these students may experience difficulties in walking, standing, and sitting using their hands. Although the institutions might have tried to accommodate them by building ramps for those with wheelchairs, there are those who might not have wheelchairs to move in the first place. Therefore, for those students it can mean that they are simply restricted in their ability to move from point A to B. Rather than the environment taking it upon itself to adequately respond to their needs, these students have to ask for services to transport them (Mashau 2015).

## Dementia

Dementia 'is a syndrome—usually of a chronic or progressive nature—in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement' (World Health Organisation 2020). Dementia negatively impacts on students' learning through forgetting what they have read when it comes to exam time, irrespective of the efforts to study. Their failure to remember does not mean that they did not study, nor they are unfamiliar with the content, but their disability hinders them. These students' self-efficacy becomes very low when they compare themselves to their counterparts. This group often goes unnoticed, as these students can just drop out silently. This need calls for institutions to provide students with study skills courses. In assessment it has been suggested that due to different disabilities different assessment tasks could be given to accommodate these diverse disabilities.

## Severe disability

According to (Surman et al. 2009), severe disability refers to an inability to use both lower and upper limbs. With this disability one cannot feed oneself, dress independently, and those who use wheelchairs, are bed-ridden, or unable to walk or even walk with aids, are included in this group. There are students with multiple disabilities which leave them with no choice but to be taken care of by people around them, either by family members or care givers who are hired to assist them wherever they are. Since policies are more focused on the exclusion of barriers, it becomes difficult to take care of students with multiple disabilities. In most cases these students drop out of the institution without any qualification having been gained.

In addition to the fact that types of disabilities can be wide-ranging, disability can intersect with a variety of other social conditions and experiences which provide a further layer of complexity to the needs of the disabled person who cannot be reduced to a single disability as constituting the whole of their identity. Examples of such intersecting experiences include:

- Poverty—there are disabilities which make people vulnerable, as they depend on others for survival, and that on its own disempowers them. According to Groce et al. (2011), lack of education is a contributing factor to poverty amongst people with disabilities, and ultimately poverty has an impact on their education.
- Social exclusion—due to the diversity of disabilities, isolation can begin early in life where a person is isolated at home, at school, in the community, as well as in the higher education institution (Landsberg et al. 2019).
- Dysfunctional services and systems—services and systems are not always available (Mutanga 2018).
- Exposure to abuse—people with disabilities are often exposed to abuse from family members, systems, as well as their institutions (Mdikana and Phasha 2018).

## Inadequacies of institutional responses

Around the world, students with disabilities metaphorically have been denied a chance to pursue their higher education studies irrespective of the policies and legislation in place to accommodate them (Mutanga 2018). Students with diverse disabilities require significant adaptations in the institutional setting to accommodate the particularities of their disabilities, which might range from physical, sensory, intellectual, to more hidden disabilities, such as communication disorders, emotional disturbances, and learning disabilities (Landsberg et al. 2019). A widespread problem is the lack of necessary resources to meet their needs. In the context of institutional lack, a disadvantaged socioeconomic status can contribute to students with disabilities from poor backgrounds (Groce et al. 2011) being even less likely to succeed in HE.

Several HEIs need to be congratulated in that they have initiated student support services in a form of Student Disability Units and some designated facilities around their institution, especially for students with disabilities. Nevertheless, significant gaps remain in the provision of support, such as inaccessible buildings and the lack of adequate available assistive devices (Mutanga 2017).

A problem arises when there is a belief that persists among teaching staff that only those in the Department of Inclusive Education or Learner Support, or Disability Staff Units, have the responsibility of knowing how to respond to the needs of diverse students with disabilities. This, and other beliefs, derail the progress of health promotion and inclusive education within the institution. Students with disabilities are not going to get adequate support from staff or administrators who lack training on disability issues (Mutanga 2017).

Many HEIs have disability and health policies in place which guide their practices (Mhona 2018). However, they lack knowledge and understanding of how to implement such policies. In inclusive education, as well as health promotion, it is believed that all students can learn, provided they are given appropriate support (Education White Paper 6, 2001). At present, however, students with disabilities' experiences include: lack of access to appropriate information and consistent support; poor enforcement of existing disability policies within institutions; lack of access to basic disability and other support services;

lack of effective alignment between different services offered within institutions; and lack of resources to meet the costs associated with adapting to disability.

Based on the students with disabilities experiences, there is a great need for HEIs as settings to change and adapt their practices to address the needs of students with disabilities. Students living with disabilities are human beings who have the right to education just like any other person without any discrimination (The Constitution of the Republic of South Africa, 1996; Mutanga 2017). In addition, the educational institutions are prohibited from discriminatory practices against students with disabilities based on their disability (Rammahlo et al. 2018). In fact, students with disabilities' need to be informed about their rights and empowered to make decisions which affect their wellbeing—and to be integrated within the whole institution, rather than relegated to its margins. Lack of understanding of the students with disabilities' experiences, leads to the provision of mismatched services and practices in the following manner:

## Window dressing

Institutions mostly focus on physical disabilities and how students can be accommodated, whereas the main problem is the institution itself: how it interprets its own policies, the curriculum, the support systems, as well as the understanding of disability on the part of staff, management, and administrators (Mashau 2015). Health promotion involves enabling people to increase control over, and to improve, their own health and requires institutions to move beyond a focus on the individual to a variety of social and environmental factors that interfere with achieving these goals (Marx et al. 1998). Moreover, for education to be inclusive, the focus should not be on the disability which students might have, but on the support which could be given in any context to enable the individual to reach their full potential (Mhona 2018).

Irrespective of what the students experience due to their disabilities, the generic standpoint can be applied through accommodating them within the whole institution, instead of window dressing the institution with wheelchairs, lifts, ramps, and an office which supports students with disabilities. HEIs need to find ways to remove barriers for students to learn in a conducive environment which does not discriminate against them because of their disability but gives students the opportunity to be independent and equal in the institution where they have enrolled (Mutanga 2017). Socially, students with disabilities can be excluded because they cannot access some of the services that should be available to them, hence their experiences in some instances are unknown since they struggle in silence (Matshediso 2007). One possible way to accommodate students with disabilities in HEIs is to give them a forum where they can participate in the formulation of policies which affect them (Mhona 2018).

## The design of the curriculum

When it comes to curriculum design, HEIs need to bear in mind that there is a diverse body of students with and without disabilities (Mutanga 2017). Therefore, the principle of equality must apply in the course design in relation to the content, learning outcomes, pedagogy, as well as the assessment methods (Mosia and Phasha 2017). Curriculum design should always consider the heterogeneity of the students, which involves students with disabilities' interactions and the institutional environment to reach the intended outcome for all. In the process of curriculum design, it is easy to marginalise students with disabilities through both the content and context of learning (Mutanga and Walker 2015).

It is incumbent upon the institution to avoid designing curricula which include some students and are conducive to their learning, and exclude others, whether in relation to social class, gender, disability, or any other measure (Mosia and Phasha 2017). In addition, curriculum designs can disadvantage some and privilege others by meeting the needs of a particular group and therefore promoting their retention to the detriment of others (Mosia and Phasha 2017). For example, PowerPoint presentations, or related visual technology, cannot be meaningful to students who are visually impaired (Sukhraj-Ely 2008). Nevertheless, a universal design approach to the curriculum can be applied. While HEIs can be contact or non-contact, the use of e-learning can be used more widely as catering for students in their own homes and in the environment where they can have support from their family members can be one mechanism for promoting their health and increase control over their learning.

## The delivery of the curriculum

The delivery of curriculum is always a concern to students with disabilities because of its exclusiveness in nature (Mosia and Phasha 2017). For instance, some students cannot participate in some programmes due to the nature of curriculum delivery and the environment created by the academic staff (Mhona 2018). The health promotion settings-based approach and the inclusive framework advocate that the delivery of curriculum needs to be flexible and accommodating to all students to ensure that they learn without any barrier (Marx et al. 1998). That means that staff members should avoid constructing their teaching based on assumptions about students' knowledge or interests and should rather use flexible approaches to ensure learning by all. For example, braille reading materials for students with partial sight or who are totally blind, and other assistive devices which support learning should be within the reach of students wherever they are.

## Assessment

Students with disabilities often experience assessment as unfair, because the methods and practices utilised do not enable these students to demonstrate what they can do (Mosia and Phasha, 2017). Bearing in mind that disability is diverse, assessment should be tailored to cater for diversity (Mutanga 2017; Mhona 2018). For example, institutions could offer students the opportunity to make choices regarding the form of assessment (Mutanga 2017). This would give them the opportunity to demonstrate their learning in an assessment that acknowledges their different learning styles. Most importantly, students should be involved in all stages of crafting assessment practices as active partners. Unless this is done, assessment styles will continue to privilege some and disadvantage others.

### Institutional commitment

The inclusion of students with disability and the promotion of health can also be hindered by HEIs (Mosia and Phasha 2017). It is in action where policies need to be turned into reality. This statement implies the commitment of institutions to ensure that there is collaboration between policies, structures, and procedures to make accommodating students with disabilities a reality (Mosia and Phasha 2017). Senior managers should lead in ensuring that health promotion and inclusive practices are followed if the participation of diverse students are to be widened.

## Barriers to the adoption of health promotional approaches

Higher education institutions are obliged to work towards promoting the health of students by increasing their capacity to gain control over, and to improve, their own health. This can only be done by putting students with disabilities' experiences at the forefront when designing policies and other institutional practices and approaches. However, there are barriers which hinder the implementation of health promotion and inclusive education in HEIs. Many institutions have policies which are meant to promote the rights of people with disabilities and most of these policies have adopted excellent international models which have proven to be successful in their approach (Mosia and Phasha 2017) elsewhere, but in South African HEIs we still lack implementation of these models (Mutanga 2017).

Despite all the documents and policies which try to define health promotion and inclusive education and the effective practice thereof in HEIs, many institutions seem to be acting out of compliance to the requirements of disability policies (Mutanga 2017) rather than embracing the spirit of health promotion and inclusion. Large misunderstandings remain at the conceptual level which institutions are doing little to address (Mutanga 2017)—for instance, health is still seen in physical terms as a response to sickness or disease (Mashau 2019). Part of the problem lies with the lack of a proactive leadership role being played by top management when it comes to ensuring enforcement of policies and putting them into practice. As a result, health promotion and inclusive education remain section or department based, and that, according to Mutanga (2017), impedes on their autonomy.

Finances are often cited as the reason why institutions are unable to respond adequately to the needs of students with disabilities (Mutanga 2018). Rather than seeing changes in settings and social and physical environments as necessary for securing the right to inclusive education and promoting the health of all students, finances are treated as an insurmountable barrier, and the needs of students with disabilities as a negotiable add-on dependent on the availability of resources.

A final barrier to mention is the lack of collaboration in the provision of services (Matshedisho 2007). Due to the nature of speciality in HEIs for the purpose of research, there is a lot of repetition and duplication of services rendered for students with disabilities (Mosia and Phasha 2017; Mhona 2018). Experiences and best practise are not shared across, and within, institutions. There is often no collaboration between the administration, examinations office, assessment experts, finance departments, individual academic departments, and the estates department. Mutanga (2017) cautions the need to avoid stereotyping by alienating students with disabilities from the rest of the student population when rendering services to them. Nevertheless, barriers in how students with disabilities are served in HEIs need to be overcome to ensure that they also participate fully just like any other student.

## Overcoming barriers

It is imperative, however, for students with disabilities to receive better quality education. This will require HEIs to revisit their current understandings of health promotion and inclusive education; move away from the deficit model to social model of understanding disability; review current policies and practices; utilise students with disabilities' experiences to further design policies and develop strategic frameworks; understand that health promotion and inclusive policies cut across all departments and sectors in the institution; and engage policy designers, senior management, staff, students with disabilities, and other stakeholders. Students with disabilities face different challenges. To accommodate students' diverse experiences in a positive way, institutions need to develop generic universal assistive designs based on fundamental standard principles. For example: 'disability' differs according to body size, mobility, as well posture. Therefore, to ensure that all students are catered for, design needs to attend to suitability of type, size, and space dependent on approach, reach, and manipulation. In other words, space cannot be designed for a particular disability. It needs to be designed to be adjustable to suit diverse needs. This is what it would mean to reduce barriers and make settings reachable to any person with any disability.

Different disabilities mean different physical strengths and capabilities, so when it comes to the design of different materials used by students, including study material, as well as other resources of learning, the design needs to enable these to be utilised by students without using more energy. It must be efficient and comfortable to use without causing any additional stress to these students.

Information and communication need to be transmitted in ways that are suitable and effective to students irrespective of their abilities (Landsberg et al. 2019). For example, online application procedures, while efficient for some, do not suit all equally.

The assistive designs meant for people with disabilities need to be made with the students with disabilities in mind and with proper testing and consultation to ensure they are accurate and error-free as to minimise any hazards and unintended accidents which may occur. Of great importance is flexibility in design. The use of assistive devices should accommodate a wide range of individual preferences and abilities. Simplicity is another important principle—implemented devices and other interventions should be easy to use and to understand regardless of the user's experience, knowledge, and skills.

So, the measures to ensure equal accommodation for students with disabilities should include: redress stress factors in the social and physical environment; improve the independence and mobility of persons with disabilities; adjustments for specific sensory requirements, including those relating to light, noise, and spatial stimuli; all physical environments within the institution should be accessible by all; provide students with disabilities with access to information and communication; ensure full participation and consultation by students with disabilities; and most importantly, provide access and participation to quality education.

## Conclusion

Ultimately, there is a huge gap between policies and how institutions treat their students in practice (Mutanga 2017; Mutanga 2013). There is also a lot of misunderstanding regarding the concepts of health promotion and inclusive education, and this is clear when they have to be turned into practice. Disability continues to be addressed in medical terms where the focus is on students themselves and communicable diseases such as HIV and AIDS, whereas it is the setting that can hinder students from learning (Mhona 2018) and which needs to change and adapt—something not usually taken into consideration. One can say that policies in institutions remain just like a symbol or a road sign which shows direction but remains in the same position for as long as it has been placed. Policies are there to serve as guidelines, but if the institution cannot apply them thoroughly it will be the students with disabilities who will experience difficulties during their studies. It is important that policy and practice should be aligned to each other to serve our students.

To accommodate students with disabilities to a point where their uncomfortable experiences are minimised, teaching and learning materials must be able to be utilised by any student with or without disabilities (Mosia and Phasha 2017). The health promotion and inclusive education focus sets out to eliminate barriers and to make the environment suitable for students with disabilities. Besides the design of learning materials to suit all students, including students with disabilities, reasonable accommodation measures should be taken seriously (Mutanga 2018). Reasonable accommodation ensures that persons with disabilities enjoy, on an equal basis with others, all human rights and fundamental freedoms. Seyama et al. (2014) confirm that, for instance, barriers to access information often reduces students' independence and freedom. The denial of reasonable accommodation to all students is a form of unfair discrimination.

Furthermore, students with disabilities can learn and have good experiences in HEIs provided health promotion and inclusive education are taken seriously to accommodate the students based on their experiences to empower them within their institutions. Moving from the focus on disability is crucial to accommodate students with disabilities in suitable settings. This will require meticulous training and advocacy beginning from management, to administrators, and to staff working closely with students. To accommodate students with disabilities within the institution equally, policies need to be transformed into practice, not only by establishing sections or departments which cater for these students (Mosia and Phasha 2017). Above all, everything which focuses on students with disabilities should be done in consultation with this group, as this will be in line with the slogan 'Nothing about us for us'.

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# PART 3

## METHODOLOGICAL PERSPECTIVES

# CHAPTER 10

## DOING DISABILITY RESEARCH: THE VALUE OF COGNITIVE INTERVIEWING

Oliver Mutanga

### Abstract

Ethical issues, when it comes to conducting research involving persons with disabilities, have not been widely investigated within the South African higher education context. This could leave students with disabilities vulnerable to exploitation by researchers. In this chapter, Oliver Mutanga investigates how disability research involving students with disabilities in South African higher education institutions (HEIs) could best be conducted ethically. The study draws on data from interviews conducted with students with disabilities at the University of Venda and the University of the Free State. The study found that the use of the cognitive interviewing approach is useful in enhancing the field of Disability Studies, as this approach has numerous benefits, particularly for participants with disabilities. These benefits include giving participants a voice during the research process, preventing the objectifying of research participants, deconstructing the unequal power relations between the participant and the researcher, promoting the handling of the interview process in a manner which is inclusive, and allowing for flexibility, for example leaving room for the modification of interview guides where necessary. The chapter concludes by emphasising how, among other things, cognitive interviewing is a valuable tool for disability researchers to explore to promote the treating of disabled research participants with respect and dignity.

### Introduction

This chapter is influenced by debates surrounding research in general (Carey 2019; Shafi 2020) and disability research in particular, with researchers raising questions about the ownership of research, involvement in research, and how disability research should be framed and conducted (see for example Goodley and Moore 2000; Oliver 1992; Watson 2019). Undertaking disability research is not easy and there have been many debates, especially concerning research ethics and appropriate methodologies for conducting disability research. Barnes and Mercer (2004) argue that disability researchers must work with disability organisations to develop user-led research with and for people with disabilities as opposed to research 'about' disability/people with disabilities. Oliver (1998) noted the concern that researchers capture the experiences of people with disabilities to develop their own academic careers rather than genuinely serving the needs of people with disabilities. He rejects investigatory research and argues that it ought to be replaced it with emancipatory approaches. Researchers have to learn how to put their knowledge and skills at the disposal of their research subjects to be used in whatever ways the subjects choose (Oliver 1992). Shakespeare (1997) argues to the contrary that research can be both purely 'academic' and nevertheless lead to the development of theories that can be used by disability activists to promote and achieve emancipatory objectives, ultimately having utility in improving the lives of people with disabilities. Some scholars have responded to the research challenges by undertaking emancipatory research—where participants are researchers and the professional researchers become facilitators in the research process (Biggeri and Ciani 2018). The conversations on this topic are particularly important for non-disabled researchers because of the assumed power relations between researchers and participants in all research—which may be accentuated by the unequal power relationship which exists between people with disabilities and non-disabled people in society in general.

Although it is acknowledged that 'to understand the lived experiences of people with disabilities, more qualitative research is required' (WHO and World Bank 2011, 46-47), there is still insufficient attention given to descriptions of the lives of people with disabilities (Singal 2010). Moreover, disability research is limited and tends to be dominated by concerns such as establishing the prevalence of various disabilities quantitatively and the effectiveness of medical rehabilitation programmes (Singal 2010). This is despite the fact that the Chronic Poverty Research Centre website (2006) concluded that:

> Whilst few research or development organisations would consider working with all male respondents or beneficiaries, it is still common practice to work with only non-disabled people. This is despite recognising that disabled people are disproportionately among those living in chronic poverty.

Furthermore, it is noted that people with disabilities are further silenced even when research studies are done because of a perceived inability to express themselves together with the inability of researchers to use alternative modes of communication to establish a dialogue with those who do not use conventional methods of communication (Singal 2010). As such, Oliver (1992) condemns disability research as a 'rip-off' that has done little, if anything, to confront the social oppression and isolation experienced by people with disabilities or initiate policies which have made a significant improvement in their quality of life.

Linked to these challenges is the conceptualisation of disability. Although language is important in framing our understanding of issues, disability language has been a contested field by researchers, activists and organisations involved in Disability Studies. For example, some researchers use the phrase 'disabled' students (Goodley 2011; Matshedisho 2007; Matshedisho 2010; Oliver 1999). For them, the term 'disabled students' is appropriate as it reflects the belief that those who are labelled disabled possess bodily or functioning differences and are disabled by social, cultural, and economic structures and systems and meanings. Other scholars prefer the term, 'students with disabilities' (Browder et al. 2008), arguing that the term 'disabled students' is inappropriate as it implies that the disability is that person's most important or significant quality.

In light of these debates and challenges, how disability researchers conduct themselves before, during, and after data collection is important. Participatory approaches, anchored in the qualitative research tradition with a focus on meaning and interpretation, give participants a right of voice. The focus is on listening to the research participants who are the real experts in knowing their situation (Biggeri and Ciani 2019). Therefore, the role of the researcher, as suggested by Turmusani (2004, 8), is to 'get involved in a learning process from and within the locality'.

Thus, research acts as a means to facilitate greater involvement of people with disabilities in the research process. As suggested by Ryan and Thomas (1987, 35), this is in contrast to early disability research where:

> Disabled people's (lack of) intelligence, characteristic appearance, behaviour and genetic make-up were identified, analysed, categorised and classified as 'defective' and on the basis of these supposed defects they were excluded from mainstream society.

## The study

To better understand research in the field of Disability Studies, to improve the interview schedule, and to recruit research participants, I decided to explore the thought processes behind responses, the feelings invoked by key concepts, and the socio-cultural, political, and economic context in which the study is set. Over a two-month period, a total of ten students, five females and five males, with disabilities were interviewed. Recruitment of participants was done purposively through a snowballing sampling method. All students with disabilities who were enrolled at the University of the Free State-—one of the study sites, were eligible to participate in this study. A draft semi-structured interview schedule and a life grid with some open-ended questions were developed in English. I drew on conceptualisations from both international and national disability work (Howell and Lazarus 2003; Jacklin 2011; Matshedisho 2010). A single set of interviews was conducted on the campus in students' residences, social spaces within the campus, and staff offices. Most in-depth interviews were done face-to-face, except for one session in which three visually impaired students also had an informal discussion with the researcher before their individual in-depth interview.

In-depth interviews focused on three basic cognitive stages that can influence the question answering process: comprehension of questions; retrieval of relevant information; and decision processes used when answering questions. Questions were posed to students and different probing techniques were used as follow-up questions to obtain in-depth data. Participants were asked the questions with the researcher taking notes and recording the interviews. After answering the questions, they were then interviewed retrospectively, with the researcher asking for other, specific information relevant to the interview questions.

Permission to carry out the study was granted by the University of the Free State. Participation in this study was purely voluntary and detailed information about the study was provided to all participants prior to consenting to participate. Privacy was ensured by meeting at times and places convenient and safe to the participants and all participants names used here are pseudonyms to protect their identities.

The basic idea behind this psycho-analytical principle is continuous refinement of the interviewer's thinking through reflection about the process and undertaking action to improve the interviewing process. This is done iteratively through an engagement with participants and self-reflection between both parties. Figure 1 depicts the systematic cyclic nature of cognitive interviewing.

## Cognitive Interviewing

Exploring a field of study through piloting or pre-testing can be a crucial stage before undertaking research, yet this is often relegated to the data collection phase in most studies. Some quantitative research studies utilise cognitive interviewing techniques for pre-testing survey questions in the exploratory research phase (Beatty and Willis 2007). The focus in these pre-test studies is mostly on establishing the underlying thought processes involved when research participants give responses. This is driven by the notion that, in order to answer questions, participants must: comprehend the question, retrieve the necessary information, make a judgment about the information needed to answer the question, and respond to the question (Collins 2003). As Hollway and Jefferson (2000) ask regarding the assumptions researchers have about their research participants: What do you, the researcher, assume about a person's capacity to know, remember and tell about themselves? In the cognitive interviewing process, participants are also given the opportunity in the pre-survey stage to suggest alternative wording and phrasing of the structured survey questions.

Faced with the challenge of including the voices of students with disabilities into the research process, cognitive interviewing, derived from social and cognitive psychology, was vital in exploring the processes by which participants answer questions, and the factors which influence the answers they provide. The approach is also used in criminology, where research indicates that it increases the quantity of information obtained and does not jeopardise the witness's credibility in court (Geiselman and Fisher 1985). In criminal psychology, the cognitive interview method is a proven technique that provides interviewers with a structured approach to help retrieve information from the memories of witnesses (Geiselman and Fisher 1985). Quantitative researchers who have used cognitive interviews argue that survey researchers have been preoccupied with 'standardising' data collection instruments and procedures, such as question wording, and have assumed that experience in questionnaire design, coupled with pilot testing of questionnaires, will then ensure valid and reliable results. However, standardisation is based on the questionable assumption that respondents are able to understand the questions being asked, that questions are understood in the same way by all respondents, and that respondents are willing and able to answer such questions.

Because a researcher is the primary data collection and analysis instrument (Merriam 1998), cognitive interviewing recognises the importance of unconscious dynamics in qualitative research. Finlay (2002) describes reflexivity as the point when researchers engage in meta-analysis, while for Moustakas (1990) it is a heuristic research—the process of internal search through which meaning is discovered. Self-reflection permits researchers to discover things in their heads that they did not know existed and may allow them to become aware of what allows them to see, as well as what may inhibit their seeing (Huff 1999). There are some tensions that arise from different social positions: for instance, in relation to class, gender and race. The use of cognitive interviewing during research can mute the distance and alienation built into conventional notions of 'objectivity' or objectifying research participants. The research process becomes more mutual as a strategy to deconstruct the author's authority (Wasserfall 1997). Social researchers can use cognitive interviewing as social critique and manage the power imbalance between researcher and participant.

## Recruitment of participants

In common with other Disability Studies research conducted in higher education, the recruitment of participants was a concern. For this study I used snowball sampling. The issue of recruitment came up during the study, and one participant summed the sentiments of most of the students:

> We get people (students) who always say, 'I am doing a disability research I need your help' but prior to that you always see them passing you without greeting. When they want to do their interviews that is when they go to the Unit for Students with Disabilities and say, 'May you please select a number of students with disabilities to be part of our study'… it's like they are using us…after the interviews their attitude is like, 'Now I don't know you'. It's quite annoying (Lerato, physical impairment).

Participants commended the way in which I had done recruitment since it divorced me as a researcher from the formal institution, and I could get honest answers rather than recruit via the Unit for Students with Disabilities. However, students with learning difficulties, whose conditions are not visibly seen, might be missed when recruitment is done only through snowball sampling. Also, recruiting participants through snowballing through a network of friends only works well if one is researching at a single and familiar institution of learning; it may prove difficult where the intention is to recruit participants at different institutions. As such, relying on the help of a Unit for Students with Disabilities is unavoidable in some circumstances.

During the cognitive interviewing process the issue of how to handle an interview was also discussed. It was recommended that options for braille and large print materials be made available for those with visual impairments, while those with hearing impairments should have sign language interpreters who are trained beforehand about the research. Besides these technical issues, some modifications to the original interview schedule were done as recommended by the participants.

## Modification of the interview guide

Initial in-depth semi-structured interviews applied life grids to examine students' experiences of childhood, family, education, friends, neighbourhood, and major significant events from their pre-school, primary school, secondary school up, and university experiences. Separating the pre-school period from the primary school period presented memory retrieval challenges to most students, and they suggested that it was better to combine the pre-school period with the primary school period.

Another issue that presented itself as a result of the cognitive interviewing were questions around pre-university education. Many studies report on the barriers and challenges of people with disabilities accessing higher education (Fuller et al. 2004; Riddell 1998). Initially, the following question was phrased in order to capture the coping strategies of students with disabilities who are already in the university:

> How long did you take to complete matric (secondary schooling)?

During cognitive interviews, it was suggested that those that might have repeated some grades might be embarrassed to state the number of years they took to complete secondary schooling. Instead, they suggested that it could be captured better by two questions:

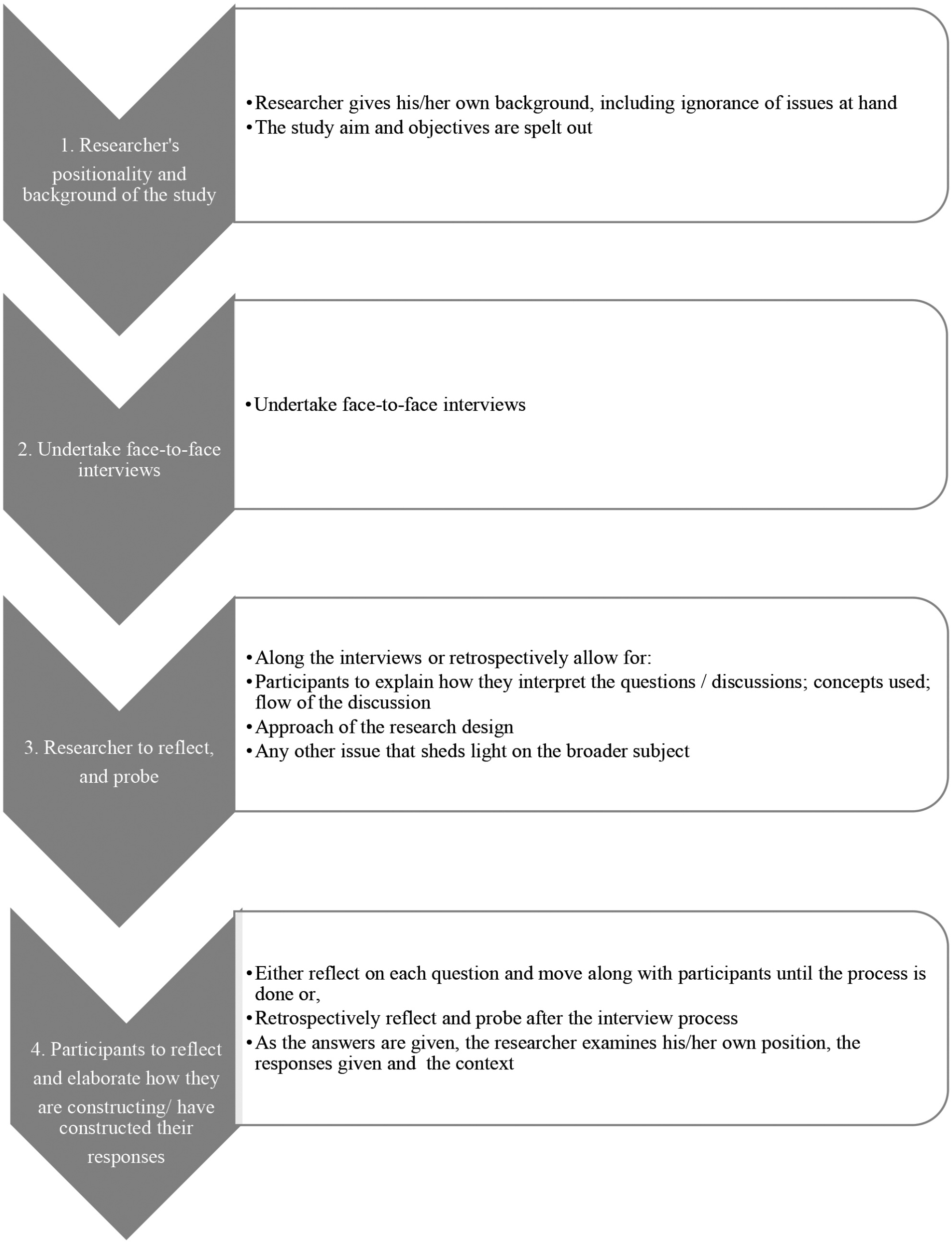
- When did you start your Matric?
- When did you complete your Matric?

At the beginning of the study, participants were told the aim and objective of the study. Then at the end of the interviews, they were asked if all the questions captured the goals and objectives. Participants suggested some additional questions that were later incorporated into the final interview schedule.

I have highlighted the major findings from the cognitive interviewing process. While these may not appear to be ground-breaking, the major highlight is that participants' views were genuinely sought and responded to. Most of the findings could not have been reached if I had used a traditional piloting approach.

## Language and disability

The cultural backgrounds of participants were varied, including Afrikaners, Zulus, and Sothos. What emerged from the cognitive interviewing approach is that not all conditions termed disability in British/United Kingdom (UK) settings are considered a disability in the cultural settings of the participants. Participants were asked about the terms used



1. Researcher's positionality and background of the study

- Researcher gives his/her own background, including ignorance of issues at hand
- The study aim and objectives are spelt out

2. Undertake face-to-face interviews

- Undertake face-to-face interviews

3. Researcher to reflect, and probe

- Along the interviews or retrospectively allow for:
- Participants to explain how they interpret the questions / discussions; concepts used; flow of the discussion
- Approach of the research design
- Any other issue that sheds light on the broader subject

4. Participants to reflect and elaborate how they are constructing/ have constructed their responses

- Either reflect on each question and move along with participants until the process is done or,
- Retrospectively reflect and probe after the interview process
- As the answers are given, the researcher examines his/her own position, the responses given and the context

Figure 1: Systemic cyclic nature of cognitive interviewing

in their own language and how these terms are viewed in general in their communities. Lwanga-Ntale (2003, 4), in his research on chronic poverty and disability in Uganda, stated that defining disability was ‘rather problematic’, as the term was commonly used for those with physical impairment, mostly of the upper and lower limbs. There was therefore an increased likelihood of ignoring those with learning difficulties. South African data reveal that the local languages seem to be laden with derogatory terms for people with disabilities. For example, in Sesotho, the local language where the university is located, they use the words, *hoseitekanele (*having something missing-mental/cognitive) and *sehole* (stupid/abnormal). Even the Afrikaans equivalence words, *gestremdheid* (physical disability) and *gestremd* (a handicapped person) are also pejorative—with a connotation of disability being a problem and people with disabilities as being abnormal. However, euphemistic terms have been adopted in some local languages, for example *bokooa* meaning disabled instead of *hoseitekanele* (Sotho for handicapped). In Afrikaans, most conditions (mental, visual, hearing impairment) are all referred to as *gestremdheid* (physically disabled—with a connotation of abnormality) without categorisations of different impairments (visual, hearing and physical) as in English. Participants allude to the fact that in vernacular, learning difficulty is not considered a disability in the local Sotho and Zulu languages, and, according to participants, its equivalent description is someone who is not smart or dull.

As a result of this cognitive interview exercise, an argument can be made that how one views disability and its variant terms is informed by culture and language. As a concept, disability is not static or universal across cultures. While it has been noted that there are controversies among disability scholars on whether ‘disabled’ or ‘with disabilities’ is the correct terminology to apply, this study suggests that there is no neutrality of a label/concept as its meaning is derived from the context and people involved. Any pre-determined concept might be inappropriate to some people while it will be accepted by others who may even come from within the same socio-cultural context. This is the same argument raised by Harriss-White (2003) that disability is a relative term because cultures define their norms of being and doing differently.

## Socio-cultural construction of disability

To some degree, the claim by the social model advocates that disability is a social construct seems to be valid. Culturally and socially, people with a disability are usually seen as a burden whose conditions should be corrected medically (Oliver 1997). International discourse on Disability Studies is moving away from this medical approach which places the responsibility of disability on individuals. For this reason, it is important to make sure that research questions are framed in a manner that does not result in perpetuating prejudices. A physically impaired student in a wheelchair was asked:

> How did you feel when I asked you the question what is your disability?

This ensured not only flexibility in addressing emergent themes but also highlighted the feelings of participants. Unlike traditional interviewing techniques, which is a one-way process of the researcher getting information from the participant, this cognitive interviewing approach enabled a dialogue even as the researcher directed the conversation.

As the researcher, I acknowledged my ignorance and probed when I did not understand well. For example, in one of the conversations I began by saying:

> I have to acknowledge I am ignorant about disability issues. You are the expert. That is why I am doing this research. Until I started this research, I didn't know the difference between disability and impairment. I will only direct the conversation but you know your situation better.

In the conversations, I posed the question:

> How does your disability affect your educational experience and performance?

All students answered this without any objections. From their answers it seems they were all influenced by the medical model, placing the onus of disability on themselves as individuals and not on the university system and structures. Nonetheless, all their answers pointed to the fact that the environmental factors (educational arrangements and social environment) and not their physical conditions were limiting them. A female participant responded that:

> It does affect my educational experience, definitely. Getting to classes, the physical structure is not accessible [e.g.] simple ramp to go to classes. If the physical structure is not accessible, your self-esteem drops therefore you drop out or perform poorly [because] you don't have confidence to ask for help (Anna, physical impairment).

A visually impaired student's answer to the same question was:

> No. I have assistive devices (Ralph, Visual impairment).

These cases demonstrate how the participants have socially and culturally accepted that their physical conditions, and not the environment (physical structure), were a problem/ barrier to their learning. Without this reflexive approach to this study, I would have been able to get information from participants, but would never have understood my own reflection on the issues discussed and the processes that unfolded during the interviews. With each interview, my own positionality in the research was being questioned and throughout the process I was defining and realising my own epistemological and ontological orientation. In this way, the cognitive process interview proved to be a reflective learning tool for both the researcher and the participants. Resultantly, the above question was reframed in a manner that allowed a focus not only on socio-environmental issues but also on their relationship to individual's activity and participation. The question was rephrased as follows:

> How does the structure/ arrangement of the educational activities make provision that accommodates you?

The question now acknowledges impairment, environmental influences as well as activity limitation. Linked to the socio-cultural construction of disability is the issue of identity and disability. An epileptic student who was part of this research did not disclose her status to the university. The main reason was that she did not consider her condition as falling under disability categories. When probed further, she said that even if she knew that her condition was a disability, she was not going to disclose her status as she did not want to be known as a person with disability:

> From a psychological point of view, you don't want to see it [disability condition]; you avoid it [if you do]; you will see it as a challenge (Jane, Epileptic).

Jane highlighted that disclosure can be disempowering, as it brings stereotyping along with it, and she was not ready to have people feel sorry for her as she 'wants to accomplish everything by herself'. Studies in other countries also report on this aspect of socio-cultural construction of disability. Kuruvilla and Joseph (1999), in their research based in rural South India, noted that a range of socio-cultural factors—particularly gender and age, type of disability, and the associated social implications and stigma of that disability—shapes people's readiness to accept disability.

## Identity

Cognitive interviewing with these students highlighted several, and in some cases opposing, views to how they perceive and feel about disability as a concept. Although all students answered the 'question what is your disability?', half of them admitted in retrospective cognitive interviews that they are not happy with the term disability/disabled. One student felt the term 'disability' is equal to 'useless', 'cabbage' and 'abnormal'. The majority of them suggested that the question 'what is your impairment?' is a better alternative. As a result, in subsequent interviews both questions were asked. Still there was no consensus. Others suggested the term 'differently abled' instead of 'disability' or 'impairment', while to some the term 'differently abled' was regarded as vague, and could mean almost anything. As a result, the question 'what is your disability?' was changed to an expanded version:

> What does being disabled and impaired mean to you? a) Do you identify/ perceive yourself as such? b) How do you think or believe others perceive you?

Further probes for this question showed that participants understood the differences between the words impairment and disability, but it could not be deduced whether those who preferred the former were doing so as a matter of identifying with a word that is less used, or really felt it was different from the latter.

All three visually impaired students and one student using a wheelchair had no problem with the phrasing of the question 'what is your disability?' One student suggested that the question should not be asked to blind students as their condition was obvious to anyone. Another student who uses a wheelchair argued that she has a disability, but she is not disabled. She said this is better for her as she feels that it makes her an individual with something.

Thus, while debates continue among researchers and academics on the concept, it might be time that in each context the voices of people with disabilities are listened to first, rather than attempting to come up with a universally accepted definition. It may also be the case that if the same question was asked to people with disabilities who are outside of a university, it might be that their answers would be different from those given by these students. Access to higher education might have enabled what Walker (2006 87) calls higher-order thinking and reflexivity to contest social labelling categories.

## Transition to higher education

Findings from the study challenge, to a certain extent, the hegemony of a discourse in South African higher education. While South African literature and media report a great deal on the under-preparedness of students from secondary schools into higher education (Mdepa and Tshiwulu 2012), this study highlights the need to look at the under-preparedness of higher education when dealing with diversity. Almost all students who were interviewed had gone to special needs schools. These are schools, also referred to as special schools that cater for disabled students who have special educational needs due to physical or behavioural problems. These schools are specifically designed, staffed, and resourced to provide the appropriate special education for children with additional needs. From their accounts, it became obvious that their educational experiences were much better prior to coming to university. Their schools were well resourced with specialists like medical doctors, therapists, psychologists, and social workers. While this is not to deny that some students are under-prepared in some other ways when they enrol for higher education, these findings challenge the long held blame shift by educationists to students and their pre-university schooling. The educational experience of students with disabilities prior to university challenges higher education to review policies with regard to provisions for a diverse student body.

## Reflections and Conclusion

Cognitive interviewing is valuable in understanding, comprehending and interpreting interview questions. In this study, this process helped in rephrasing some questions and adding other important questions for consideration. In addition, it provided some invaluable insights on how to address the concerns of undertaking disability research through the suggestions given by participants. It is worthwhile mentioning that some of the questionnaire phrasing that was reworded, for example, ‘what is your disability?’, has continuously been at the centre of debate among different researchers and activists. This has been reported by other scholars as well (Goodley 2011; Oliver 1997).

Beyond pre-testing the comprehension of questions, the cognitive interviewing technique explores the socio-cultural, political, and economic context within which the participants and researchers are based. While disability researchers continue to grapple with an accepted definition of disability, this study provides insight by highlighting the diverse views from people dealing with disability daily. It might be time to shift focus away from a universally accepted definition, and rather accept that the reality might be that disability is sufficiently diverse so that it should be context specific and socially and culturally varied.

This chapter contributes to Disability Studies and higher education research by applying an approach that has been used extensively in other fields like healthcare (Murtagh et al. 2007; Rebok et al. 2001) and criminal psychology (Maras and Bowler 2010; Menon et al. 2010). Discussions from this study contribute to the debate around the struggle of reconciling the tasks of producing research accounts that are of value to both professional institutions and people with disabilities (Goodley and Moore 2000; Shakespeare 1996). By involving those who will be part of the research from the stage of exploration of the field, I was able to challenge my own assumptions and opened avenues for researching with, and not about, disabled students (Goodley 2011). While disabled scholars like Oliver (1997) are sceptical about non-disabled people undertaking disability research, it should be acknowledged that a problem arises when a researcher assumes the role of an expert and consequently participants are treated as objects only good enough to respond to questions with little positive input to the overall research process. I have advanced a case that the extent to which participants' voices are represented, and how this is done, depends on the researchers' methods of data collection and reporting. How a research study is designed and how it is administered influence the way participants will respond and the results that will be found.

It has been frequently reported that people with disabilities do not want to disclose their status, and when they do, they underreport some of their conditions. Approaches to overcome this have focused on the phrasing of questions and building of rapport between the researcher and the participants. This study revealed that while this is important, it are not enough. Participants felt comfortable with the mere acknowledgement of the motives behind using already existing phrases and how their own views were important in constructing an inoffensive user-friendly design. Their main concern is self-respect and dignity and not being treated as people of lesser value. Such admissions could only come through an approach like cognitive interviewing.

The major thread cutting across the findings of this study is that the cognitive interviewing approach authentically manages to bring participants' issues to the fore. Through cognitive interviewing, the study brought out four core issues that are related to experiences of disabled students in South African higher education, namely language and disability, socio-cultural constructions of disability, identity, and transitions to higher education. This approach was applied on a small scale and further studies are needed to prove its usefulness as a valuable research practice tool for understanding, comprehending and interpreting questions.

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# CHAPTER 11

## SHARING RESPONSIBILITY AND MOVING OUT OF OUR COMFORT ZONES TO ACHIEVE INCLUSIVE EDUCATION

Desire Chiwandire and Louise Vincent

### Abstract

Despite the enactment of various policies having helped to increase the numbers of students with disabilities in South African higher education institutions (HEIs), securing favourable throughput and retention rates for students with disabilities continues to be a challenge. In this chapter, Desire Chiwandire and Louise Vincent investigate the idea of ‘responsibility sharing’ on the part of relevant stakeholders (who include Disability Unit Staff Members (DUSMs), lecturers, HEI leadership and management, and students with disabilities) as a necessary step towards improving the prospects for success of students with disabilities in higher education. The chapter draws on interviews with DUSMs at a range of South African universities. It argues that achieving the goals of inclusive education requires higher education actors being willing to ‘move out of their comfort zones’, rather than confining themselves to their traditional roles and conventional responsibilities. This includes, for example, DUSMs playing a watchdog role; students with disabilities developing self-advocacy skills and being willing to self-disclose their disabilities. Lecturers need to be willing to consult with students with disabilities on how to support students with disabilities in the learning process best. University management needs to work collaboratively with DUSMs and invest financially in professional development courses aimed at equipping lecturers to respond better to the specific needs of students with disabilities. The chapter argues that disability policies are not enough to achieve meaningful inclusive education for students with disabilities, and that universities

need to set out clear responsibility-sharing guidelines to facilitate effective cooperation between relevant stakeholders if these institutions are to make inclusion a reality.

## Introduction

> Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the changes necessary for full participation of people with disabilities in all areas of social life (World Health Organisation (WHO) 2001, 28).

On 30 November 2007, the South African government ratified the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which resulted in the country assuming obligations to promote inclusive education as a central educational approach for ensuring that students with disabilities can flourish in higher education institutions (HEIs). Previously, with the advent of democracy in 1994, the South African government undertook various initiatives aimed at greater inclusion of historically excluded students with disabilities. These initiatives aimed to ensure that students with disabilities 'are not discriminated against on the basis of their learning needs' (Howell and Lazarus 2003, 72). As Dalton et al. (2012) have noted, South African disability policies have aimed to achieve a holistic form of inclusive education whereby educational institutions remove as many barriers to learning as possible for students with disabilities to be effectively educated side by side with their non-disabled peers. Although the enactment of various disability policies has been commended for increasing the numbers of students with disabilities in South African HEIs, these institutions continue to grapple with securing favourable throughput for, rates and the retention of, students with disabilities (Bell and Swart 2018; Chiwandire 2019; Mutanga 2019; Lyner-Cleophas 2019).

From a South African higher education (HE) disability policy framework standpoint, concerns have been raised about how 'the management, resourcing and funding for disability rights in Post-School Education and Training (PSET) remains fragmented and separate from that of existing transformation and diversity programmes at institutional levels' (DHET 2018, 12). Clearly, disability policy documents alone cannot achieve the goals of inclusive education. There is a need for responsibility sharing and collaborative initiatives amongst the relevant stakeholders involved in achieving inclusive education for students with disabilities in HEIs if these institutions are to support students with disabilities effectively (Bryan and Myers 2000; Eckes and Ochoa 2005).

Globally, the need for the collaboration of stakeholders involved in achieving inclusive education has been widely noted. In the United States, for instance, Bryan and Myers (2000, 20) argue that 'including students with disabilities in all programmes and activities begins with collaboration across campus and a willingness to craft a broadly accepted vision of how inclusion will be achieved and who will be involved'. Bryan and Myers (2006) further argue that achieving inclusive education through effectively supporting the learning needs of students with disabilities should not only be considered the responsibility of Disability Units. Rather, they suggest that it should be a shared responsibility among 'all members of a campus community—administrators, faculty, staff, and students with and without disabilities' (Bryan and Myers 2006, 18-19).

In the South African context, the Strategic Policy Framework on Disability for the Post-School Education and Training System, for instance, has called for the Department of Higher Education and Training (DHET) to 'ensure cooperation and coordination between the relevant stakeholders' to achieve inclusive education for students with disabilities within the PSET system. The White Paper for Post-School Education and Training has referred to such relevant stakeholders as 'including lecturers, support staff and management' who should all actively be involved in addressing disability at all levels of the PSET system (DHET 2013: xv). As Mutanga and Walker (2017, 8) have argued, these stakeholders' collaborative efforts and shared responsibility is important in creating a supportive HE educational system to make the inclusion of students with disabilities a reality.

The aim of this chapter is to investigate this idea of 'responsibility sharing' on the part of relevant stakeholders in the university setting. In particular, the chapter examines the possibilities for achieving the goals of inclusive education if those involved are able to 'move out of their comfort zones' by not only focusing on their traditional roles and conventional responsibilities. This chapter is based on interviews with 28 Disability Unit Staff Members (DUSMs) at ten different South African universities in which we sought to gain an insight into how shared responsibility is achieved in practice. DUSMs were chosen as key informants because of their direct involvement with students with disabilities and their experience of liaising with all stakeholders on campuses from top management to students to academic departments.

The data were analysed deductively using the concepts of 'comfort zone' and 'responsibility sharing' derived from the literature on inclusion of persons with disabilities in HE. We were particularly interested in whether or not relevant stakeholders' actions demonstrated a willingness to move out of their comfort zones in addition to honouring their conventional responsibilities and the implications that such actions had in achieving inclusive education. Ethical approval to conduct this research was granted by the Rhodes University Ethical Clearance Committee.

## Comfort zones

What does it mean to 'move out of our comfort zones'? There is literature on this idea, in which 'comfort zone' is defined as 'a mental state characterised by a decision-maker operating with a sense of comfort and security' (Bourmistrov and Kaarbøe 2013, 197). The concept of comfort zone as argued by Kiknadze (2018, 5-6) 'helps to conceptualize people's relationships to approach-avoidance conflicts in which people are motivated to engage in a behaviour or activity yet hesitate to do so because of opposing motives to avoid the behaviour'. Students with disabilities' presence on South African campuses contributes to the diversity of our campuses, and as such is a resource for learning and growth. We can, however, only positively draw on this resource if we are willing to move out of our comfort zones and foster the meaningful inclusion of students with disabilities.

By ‘inclusive education’, we have in mind education that ‘aims to improve the learning and active participation of all the students in a common educational context’ (Moriña 2017, 3). The goal of inclusive education policies is to create institutional environments that are conducive to the thriving and success of all students, regardless of their background, physical makeup, culture, language, gender, sexuality, or prior experiences.

Mutanga and Walker (2017) have criticised South Africa for not having a formal national disability policy which provides for the standardisation of disability inclusion within universities. However, inclusive education is not just achieved at the policy level. Inclusive education requires every participant in the higher education context to be willing to challenge their preconceptions about how things are done, how they relate to one another, and what they regard as ‘normal’ or conventional at every level, from teaching and learning, to management and administration, socialising, work behaviours, and the physical environment of campuses. Studies investigating the role being played by relevant stakeholders (including lecturers, students with disabilities, the university management, and DUSMs) in achieving meaningful inclusive education for students with disabilities have reported on the tendency of all role-players to shift responsibility onto each other, instead of sharing responsibility in a meaningful way.

- Lecturers

South African studies which explore lecturers’ experiences of teaching students with disabilities show that lecturers tend to deny their obligations with respect to inclusive education and to shift this responsibility onto others—Disability Units, for instance. This has slowed progress towards achieving the goals of inclusive education in HEIs. For instance, (see Van Jaarsveldt and Ndeya-Ndereya 2015; Lyner-Cleophas 2016) lecturers say that they are ill-prepared to teach students with disabilities, and that, as a result, their only option is to resort to referring students with disabilities to Disability Units. Other studies (Howell 2006; Ndlovu and Walton 2016) have reported that some lecturers associate disability with incapacity to learn and succeed in an inclusive academic environment.

The comfort zone for lecturers is teaching non-disabled students or perhaps those students with disabilities whom they deem easy to support within the classroom setting. Those students with disabilities who they deem not to meet this expectation or who are assumed to be unable to succeed on an equal footing with their non-disabled peers are routinely referred to Disability Units. So, for lecturers, for example, moving out of comfort zones would mean being willing to adopt new, innovative teaching practices that enable them to teach diverse students more effectively (see Taha et al. 2015, 1920). By innovating in their own teaching practice, lecturers can be catalysts for getting students out of *their* comfort zones, and into what Taha et al. (2015) have referred to as the ‘stretch zone’ or ‘learning zone’. As they elaborate: the stretch (learning) zone is not very comfortable, however, it is stimulating as students are exposed to opportunities to do and try ‘new things, gain new experience, they are motivated, and (as added value) there is often a good atmosphere and fun in seminars and lectures’ (Bourmistrov and Kaarbøe 2013, 197). Integrating new information and communications technologies (ICT) into classroom practice to achieve more blended learning styles to enhance the learning experience of students is another way in which lecturers can innovate (Applebee et al. 2004).

Research (Arkoudis et al. 2013) suggests that lecturers can, through their teaching strategies, promote greater interaction between diverse students who might not otherwise seek one another out. Research finds that when students are encouraged to move out of their comfort zones, and to encounter one another, this helps reduce prejudice and challenges stereotypes (Vandeyar and Mohale 2017). Rather than seeing diversity as a barrier to be overcome, lecturers who are willing to operate outside of their comfort zones are able to utilise diversity as a resource. Arkoudis et al. (2013, 233) found that when students are provided with opportunities 'to move out of their cultural comfort zones', they benefit by developing their confidence in interacting with diverse students whom they might initially experience as being 'other' to themselves.

- Students with disabilities

Students with disabilities can also challenge the boundaries imposed by their own comfort zones. In a study by Eden (2014, 266), the author evaluated 26 in-depth reflective essays on the diverse experiential learning reported by undergraduate Geography and Environmental Management students on part-time, unpaid work placements in the University of Hull, England, from 2011 to 2012. This study found that most of the students 'wrote about being pushed out of their "comfort zone" of skills, knowledge and social context, forcing them to be, or at least recognise the need to be, more proactive, to tackle unfamiliar activities and ideas and thus to develop emotionally and engage more fully in their work experience' (Eden 2014, 266). The author concluded by encouraging universities to enhance work-based learning about employability through integrating learning in the workplace with learning in higher education (Eden 2014).

Research suggests that students with disabilities may shift the responsibility for their inclusion onto lecturers (see Bell and Swart 2018; Mutanga and Walker 2017; Vergunst and Swartz 2020; Lourens and Swartz 2020) and DUSMs (see Lourens 2015; Van Der Merwe 2017). Students with disabilities themselves can do more to share responsibility, rather than expect to transition to a barrier-free higher education environment.

- Disability Units

As for DUSMs, their comfort zone is having limited responsibilities, especially those associated with supporting the academic inclusion needs of students with disabilities, as this is the conventional responsibility of their portfolio. Most DUSMs express discomfort with expectations that they should be responsible for wider forms of inclusion, such as social inclusion.

There are also studies which have documented the measures taken by DUSMs in supporting the academic needs of students with disabilities in South African HEIs (Chiwandire 2020; Chiwandire and Vincent 2017; Mutanga 2015; Ntombela and Soobrayen 2013; FOTIM 2011). The dominant finding of these studies is that although DUSMs are trying their best to facilitate the academic inclusion of students with disabilities, they have raised concerns about university management personnel not being cooperative and being unwilling to work collaboratively with DUSMs in addressing disability inclusion matters (Chiwandire 2020; Chiwandire and Vincent 2017). In other studies (FOTIM 2011;

Chiwandire 2020), DUSMs have reported that the goal of achieving meaningful inclusive education is frustrated by their lack of autonomy and the absence of direct communication channels with university management. This is especially important given the role played by the university management in decision making related to budget allocations to various departments, including Disability Units (FOTIM 2011).

- University management

Finally, the comfort zone of university management is not investing financially in disability inclusion initiatives and taking a foot-dragging approach when doing so, as well as shifting all the responsibilities relating to the inclusion of students with disabilities to DUSMs.

Ramaahlo et al. (2018, 263) have recently argued that the involvement, or rather non-involvement, of university management personnel has an impact on whether or not students with disabilities will have equal participation ‘in the university environment, including successful and timely graduation’. To date there is no South African study which has specifically explored the experiences of this group regarding their involvement in supporting students with disabilities. Thus, much of what we know about the involvement of university management personnel has been discussed in studies which explore the experiences of students with disabilities and DUSMs. The dominant findings from these studies (FOTIM 2011; Ntombela and Soobrayen 2013; Chiwandire and Vincent 2017; Chiwandire 2020; Basson 2014) report university management personnel’s reluctance to invest financially in disability inclusion matters, lack of familiarity with their universities’ disability policies, and a shifting of responsibility for issues related to the inclusion of students with disabilities onto DUSMs. Thus, the overall impression is that university management personnel at South African universities are not effectively supporting DUSMs to create a welcoming culture for students with disabilities in these institutions.

## South African DUSMs experiences of stakeholders moving out of their comfort zones and sharing responsibility

One of the challenges reported by DUSMs is with the staffing of Disability Units themselves. As Deidre points out, DUSMs are involved with complex ethical questions and decision-making processes:

> You will get Disability Units at higher education institutions where, maybe an Admin Officer who can apply for a job and may become a Disability Coordinator. My view on that, is that universities should rather have a professional person who will know how to coordinate the unit. Being a professional person with ethical standards and stuff like that, rather than grabbing someone with no human skills, background, put them in that position. I would think rather have a professional person in that position, because there is a lot of things, ethical things that you can get in trouble with disability related stuff, you know. If you are the one in control of the Disability Unit you have to make a decision on whether or not, say, for instance, a person has to get a bursary based on their disability and you make a wrong decision, what can the university do because you don’t really have

> that background of working with persons with disabilities. You don't have a professional council where a person can go and report you.

Similarly, Thokozani argued that there are high level skills and capacities that are required of staff members working with students with disabilities:

> It is important to train staff members as far as disability issues are concerned. Don't just say because someone did a technical course…that that person will be able to help students with assistive devices…You find people saying 'I have been working at this institution for 5 years, I have 5 or 8 years as a technical officer', but if you put that person in the Disability Unit—the person has never been exposed to issues of disability, so it becomes a challenge for that person to be able to help students…People think that just because they have worked in institutions of higher learning they can be able to handle any students with disabilities. It's not like that. When it comes to students with special needs, it's a different field altogether.

Another dimension of the work, as Craig pointed out, is requiring advocacy skills to speak out against any forms of injustices perpetuated by HEIs towards students with disabilities:

> I tell them we need to address these issues, because it's a human rights violation against the Constitution of this country, and then that person will be too scared to become involved because they are staff. You know people don't know the law. They don't know the legislation. Being in contact with people with disabilities for a very large part of my lifespan, I know these issues. So, problems are not being solved because people are just being scared to take these things head-on.

The watchdog role and advocacy role that Craig alludes to is, for many DUSMs, not within their comfort zone. It involves, as Craig explains, someone who experiences themselves as 'lower ranking'—as a DUSM—intervening with people who traditionally have greater power, status, and authority:

> To give you an example: I had a student with a disability who came to complain to me that his lecturers didn't want [to] grant him extra time for this test. The lecturer was refusing, because, in his opinion, he didn't think it was necessary because of the type of test he is giving them. But the lecturer was not in the position to make that decision. So, I spoke to one of my superiors to speak to the Dean of that Faculty so that we could have high level intervention to make sure that this problem was resolved efficiently and properly. This is because I'm quite a low-ranking person. I can't go outside one department and tell someone what they can do and cannot do, and this person above me was too scared. You know they were very scared to have their name in writing connected with this case, so I was told to draft something which I did. I was told later to put my name on this draft as well, and send out the letter, because this person was too scared to be associated because they don't know what the implications are of becoming involved. And that is a product of non-inclusive education system. I'm convinced of that because

> people in general just don't know how to deal with disability issues, because they have not had exposure of people with disabilities because of you work with people with disabilities you become aware of their needs and what is right and wrong and what is reasonable and unreasonable in terms of what they require. The case was resolved, and I managed, from my point, to resolve that, but there is lots of things and attitudes that needs to change. The best way to do that is to have people in contact and be aware of what is going on with disability issues in the country.

For DUSMs to hold lecturers to account for violating students with disabilities' rights to inclusive education is uncomfortable for many of these staff members, because it disrupts the traditional hierarchy of the university and interrupts comfortable assumptions about lecturers' authority and autonomy:

> That's exactly what happens. Students with disabilities are often referred to the Disability Unit by their lecturers, or, in other cases, students with disabilities are just ignored, you understand. That's why I centralise everything and I do approach all the new employees so no one can tell me that they have never attended an awareness session from my office, or from our other campuses, because I keep a portfolio of evidence to show that, you know what? Thandie [that is the name of a new employee] was here and he did not refer accordingly, so if Thandie maybe comes and say 'I didn't know of a student', that the student has proof that he went to Thandie. Then he would say 'I don't know about you', then I say 'ok, here is my portfolio. You signed on this day on the new employee orientation programme, how can you say you don't know about our services?' So I'm also covering my back in terms of admin-related staff. So I'm working for the university and for the students with disabilities too (Deidre).

In many countries, including South Africa, DUSMs are conventionally charged with such responsibilities as liaising with various university departments and lecturers on how best to address the academic needs of students with disabilities (Howell 2005). Some DUSMs are moving away from restricting themselves to these conventional responsibilities to focus more on playing an advocacy role, becoming agents of change rather than merely playing a support role. This might include building alliances and co-opting allies within their universities. It might involve, for example, working to gain the support of university management for disability inclusion initiatives on campuses. It might also involve DUSMs making sure that they are represented on various university committees as one strategy for mainstreaming disability inclusion issues as well as advocating for the rights of students with disabilities in ways that reach the wider non-disabled university community:

> We are also lucky enough to be part of many committees, so once we raise, once we raise awareness with your higher management, it automatically filters down into what everyone does. So, from Web building to Accessibility to Curriculum Design hopefully they will also at the back of their minds think how about disability, 'how can this be adapted?' So, I sit on the Wellness Committee which looks at the wellness of this university in its totality. I sit on the Concession Committee

> which looks at approving their concessions for students with disabilities. I also sit in an MEC Committee for people with disabilities where staff and students with disabilities issues are discussed at an MEC level, and decisions are then taken filtered down from there (Zoe).

Another way in which DUSMs are moving out of the comfort zone of their traditional, campus-based academic inclusion role is regarding the facilitation of post-university employment for students with disabilities as one of their core responsibilities. South Africa's 1998 Employment Equity Act (EEA) aims to equalise employment opportunities for persons with disabilities, outlawing discrimination on the grounds of disability. Nevertheless, persons with disabilities continue to be the country's largest unemployed population. And, as we know, employment is vital for 'reducing welfare dependency and social exclusion' (Meager et al. 2007, 3). DUSMs can play a critical role in helping students with disabilities gain work experience so that they are more employable after university. As Zoe explains, this vital role is not the traditional expectation of the DUSM:

> As the Disability Unit, we also assist with recruitment so companies will approach us directly and say we would like to get in touch with job placements. So things like that, that's not teaching and learning stuff, and yet we have avenues that students with disabilities can be placed for work experience. So even find[ing] a job easier after university. So those are some of the things that we do. Many universities think that their job ends when that student gets their certificate. We work a lot with companies that employ our students to ensure that the support can continue, and the student does have a voice.

Within inclusive education debates embracing diversity is one of the major responsibilities of lecturers. One of the ways in which lecturers can exercise this responsibility, as argued by Moriña et al. (2013, 3), is through modifying their teaching and learning practices to the extent that they are 'as inclusive as possible' of students with disabilities. South African disability policy calls for lecturers to embrace diversity in the classroom setting through designing and teaching a flexible curriculum that can promote the academic success of students with disabilities (DHET 2018). In addition to curriculum design, scholars (see Baker et al. 2012; Thomas 2016; Moriña 2019) have argued that lecturers can contribute to the academic success of students with disabilities by showing an interest and exhibiting empathy. These studies show that lecturers who take an interest in students with disabilities and create what Moriña (2019, 7) refers to as a 'good classroom climate' are more likely to motivate this group in the learning process. This might include, for example, making students with disabilities feel like just any other student, providing personalised attention where appropriate, and using positive reinforcement (Moriña 2019).

Inclusive classrooms in which students with disabilities can thrive could be created if lecturers take an active interest in the learning process of students with disabilities. But in the experience of DUSMs, taking responsibility for creating conducive classroom environments and empathising with students with diverse learning needs, stretches many lecturers far out of their zones of comfort.

> [For some lecturers] it very easily becomes oh just send it to the Unit for Students with Disabilities (USD)—they will sort it out. So, a lecturer would not take responsibility themselves to figure out 'how should I teach this student', 'how can I support this student', because they don't have to take ownership, because they have shifted it to the Disability Unit. Why should we always be the one who must assist students with disabilities? We can tell lecturers that we can help them on how to make adjustments for the students, but to just refer them back to the Disability Unit all the time you are separating them from other students again, and that's not inclusive. That's exactly what happens—students with disabilities are often referred to the Disability Unit by their lecturers, or in other cases students with disabilities are just ignored, you understand. (Deidre).

For Mitchell, creating a 'good classroom climate' begins with lecturers transforming their mind-sets and making an effort to honour their professional responsibilities of supporting students with disabilities on an individual basis instead of referring students with disabilities to Disability Units:

> We want to change that, because we always don't want people to come to us for help. We want to create the mind-set of 'I don't want to refer this all the time to the Disability Unit'. We want other people, other academic staff, specifically to deal with these kinds of issues [referring to supporting students with disabilities] as well, because then the mind-set will change. So, they will also start thinking of solutions on how you accommodate a person with a disability, because you have to get used to it—it's a reality. You need to be prepared for these kinds of things. All departments, every faculty, and everybody needs to be involved campus-wide.

As Debbie cautions, lecturers who do not come out of their comfort zones to accommodate students with disabilities in diverse learning processes fully negatively affect not only the educational experiences of students with disabilities, but non-disabled students' education as well. The assumption that students with disabilities are unable to participate equally in group activities is a prominent example.

> The other thing is where you have lecturers that think because you are deaf, maybe you should do this assignment on your own. So, they exclude the student with a disability from a group experience being part of a learning experience you know with other students. So, they are not only excluding a student with a disability from the group, but they are also denying the non-disabled students to experience a student with a disability, because they can learn things from each other. So, when a lecturer makes a decision like that, then you exclude both parties from the learning experience (Debbie).

But there are also examples of lecturers working closely with DUSMs to understand better how best to teach students with diverse disabilities in their classrooms.

> I work well together with the academic staff and they will contact me and say 'this is what we would like to do, how can we do it?', 'this is the exam that we

> are setting or a test we are setting, have a look at it and see if there is…[anything] problematic so think about it and advise us. (Claudine).
>
> We address practice barriers as well. That's the way things are done in the institution. You know, there is a constantly an evolving process where teaching methodology is being inducted to accommodate people with disabilities. Lecturers work very closely with us whenever there are students with disabilities in their classes. So we usually discuss effective solutions, for example, what is the best method in a lecture when a class is being presented? What is the best method for having a student to have access to his information for his studies? What are the best practices in the higher education sector? You know we benchmark a lot with other universities as well. So, we establish best practices (Craig).

Rather than expecting lecturers to automatically have the knowledge and skills to implement best practices for inclusion in their classrooms, training and support is needed. But this cannot be yet another unshared responsibility left up to Disability Units. The involvement and financial support of university management is needed for professional development programmes aimed at equipping lecturers with the necessary capabilities for teaching and supporting diverse students with disabilities.

When it comes to the responsibilities of students with disabilities themselves, disability disclosure, especially during the application process, has always been emphasised as critical to enabling universities to make advance preparations to reasonably accommodate diverse needs (Department for Business, Innovation and Skills 2014). Article 24 of the UNCRPD obligates South African HEIs to provide reasonable accommodations and appropriate support tailored to students with disabilities individuals' learning needs (United Nations, 2006). South African higher education disability policy requires all students with disabilities to self-disclose their disability if they are to receive appropriate accommodations.

As Mutanga (2013, 77) puts it, students who fail to disclose their disability 'will remain in the eyes of institutions non-disabled'. Students with disabilities who do not officially disclose their disabilities, as DUSMs have pointed out, run the risk of not receiving reasonable accommodations, and this has, and can, put their academic success in jeopardy. Given this, DUSMs have highlighted that disclosing one's disability is part of good practice, not only because this will mean that students with disabilities are eligible to receive reasonable accommodations, but because it also helps lecturers to be prepared in advance for how they can best support the individual learning needs of these students. On the other hand, universities cannot compel students with disabilities to disclose their disabilities as doing so would be in violation of these students' 'right to privacy' (Matthews 2009, 230).

DUSMs at times experience frustration when students with disabilities (especially those with invisible disabilities) do not self-disclose at enrolment, which creates barriers to their own inclusion, and eligibility for reasonable accommodations which are necessary to their academic success, difficult to surmount.

> Most of them [referring to students with invisible disabilities], especially the ones with learning disabilities, they tend to just go about things on their own, you know,

> until such time they can't anymore or they feel that they really, really need help—they are struggling—then they come to us for assistance. But there are some [who] from the get go [that] do come to the Disability Unit, and say 'look, this is my problem I'm going to need help' (Riska).

> What we often find is that when students come to university as first years they feel like they can do it on their own now. So, in their first year, they might feel like 'oh no 'I don't need this really' [that is, the support of the Disability Unit]—especially a student with a diagnosed learning disability. So, they may feel like 'I'm big now, I can do it on my own'. They decide not to disclose, or they might be in fear of stigma and stereotypes. But then they are forgetting about the volume of the work, and then, like, say this time of the year after their first exams, they will realise that 'but I'm really struggling', and then they will come forward (Charmaine).

While it is difficult to help a student who has not self-disclosed a disability, we also need to ask why some students with invisible disabilities do not officially disclose their disabilities before facing serious academic challenges. Self-disclosure is not comfortable for many students. The fear of stigmatisation alluded to by Charmaine is echoed in a number of studies' (see for example Vergunst and Swartz 2020; Mutanga 2019) findings that students with invisible disabilities have attributed the reluctance to self-disclose their disability status out of fear of being stigmatised by the non-disabled university community. Thus, the responsibility to self-disclose on the part of the student goes hand in hand with the responsibility of the university to be a place that is conducive to such disclosure.

It is also the case that inclusive education should not necessarily be premised on self-disclosure. Inclusive education means that curricula are designed to support the learning needs of diverse students regardless of whether a disability has been disclosed or not. If lecturers were to leave the comfort of their existing curriculum design practices to adopt universal design for learning (UDL) principles it would enable them to deliver an inclusive curriculum despite some students with disabilities choosing not to self-disclose their disabilities (Schelly et al. 2011).

Shouldering the responsibility to self-disclose a disability is one of the ways in which students with disabilities can contribute to their own success at university. Another is self-advocacy. While it is the case that lecturers have the responsibility of removing barriers inhibiting the success of students with disabilities through adopting inclusive teaching strategies which support the learning needs of this group, DUSMs emphasise that students with disabilities themselves should acquire self-advocacy skills to enable them to be involved actively in creating inclusive higher education environments in which they can flourish academically and personally. As Matthew describes, through self-disclosure and advocating for themselves, students with disabilities can play a central role in changing the mind-sets of other role-players in the learning encounter:

> We always tell our students at the beginning of the year to introduce themselves to lecturers: to say 'these are the accommodations we need', and things like that, and usually from that first interaction the lecturer will then, if they have never lectured a person with a disability before, whatever, will actually then change their mind-

> set in terms of lecturing style or what type of material they put up. And if it's a blind student, a visual thing won't help, it has to be an audio type of lecture where they would then talk about things in detail, and not just say it's on the board. So, I think in the past couple of years we found out that lecturers come on board, say 'come talk to us', 'how can we improve our lecturing style because we met this student'.

Students with disabilities also have the responsibility of communicating directly with their Disability Units. Debbie describes how this helps the DUSMs to understand the barriers to success that are being experienced and find viable solutions:

> Communication, constant communication. The contact with our students assists us to identify the barriers, and then it's for us to make the contact with the lecturer or the residence or whoever to talk to them about removing the barrier. So, the measures are the communication, constant communication and raising awareness and inform them. So, students come to us individually and tell us we have problems with one, two and three. So, we get the barriers. Now we make contact with the different role players and tell them: 'this is a problem, this is a problem, this is how we can solve it', whatever (Debbie).

Where self-advocacy and communication does not come easily, some Disability Units become involve in teaching assertiveness to students with disabilities so that effective communication of their learning needs to lecturers is made possible. This is an example of both students with disabilities and DUSMs going beyond the boundaries of their comfort zones to find new ways to improve the higher education learning environment. Taking self-advocacy a step further, Debbie spoke about involvement in disability activism as one of the positive strategies which students with disabilities can utilise to break down barriers hindering their full participation in campus life. One form that disability activism can take is involvement in Student Representative Councils (SRC):

> This year for the first time there was a blind student who was a Student Representative Council (SRC) member, and she went to great lengths in creating awareness. Every meeting that she attended created awareness. So, using the student with a disability as well to create awareness also works, because she went out and took the Rectorate one day and she told them: 'you are blind', 'you are deaf today', 'you are not allowed to speak to anybody you have to sign'. I mean, the person doesn't know sign language even. So she forced them to spend their normal day as a deaf person, as a blind person, as a person in a wheelchair. The Dean of Student Affairs was asked to be in a wheelchair for the day—she realised that when she was in this wheelchair in her building, her office where she works every day, she cannot go to the bathroom; she cannot enter the building; the lift is not working. And then she realised that students with disabilities don't feel welcome here. And then she has now changed her bathroom to a wheelchair accessible bathroom. She has now put in a new lift in her building. She has changed the doors because she experienced it herself (Debbie).

For these DUSMs, helping students with disabilities to find their voice and advocate for themselves is part of their role. This is especially important given that research suggests (Chiwandire 2017; Chiwandire 2020) that it is only a minority of students with disabilities who feel confident to use their self-advocacy skills to effectively communicate their learning needs to lecturers and others. Equally important is that calls for self-advocacy do not become another way of blaming the victim and disowning the responsibility to provide equal access' (Osborne 2019, 229).

## Conclusion

In this chapter we have underlined the importance of all relevant stakeholders contributing to the goal of achieving inclusive education. The refusal of meaningful shared responsibility and an unwillingness to move out of our comfort zones, rather shifting responsibility onto one another, makes achieving this goal more difficult. Moving out of our comfort zones could take the form, for example, of DUSMs facilitating post-university employment for students with disabilities; educating and sensitising lecturers on how best to support students with disabilities; putting in place monitoring mechanisms aimed at holding lecturers who do not comply with their professional obligations to support students with disabilities to account; fearlessly playing a watchdog role against those who might potentially violate the rights of students with disabilities; and finding creative ways of penetrating universities' bureaucratic structures by building alliances and co-opting allies, especially individuals who are influential in decision-making processes with regard to issues related to accessibility.

When it comes to lecturers, moving out of our comfort zone asks that we go beyond our traditional responsibilities and assume new responsibilities, recognising diverse student needs and adapting our curricula and teaching styles accordingly. It involves also adopting an inclusive outlook and cultivating positive attitudes towards supporting students with disabilities in the classroom setting.

Students with disabilities also need to be part of responsibility sharing and can also move out of *their* comfort zones by assuming such new responsibilities as acquiring self-advocacy skills which will enable them to navigate potential higher education challenges successfully. Along with self-advocacy, timeous self-disclosure of disability in order to obtain the necessary support to succeed in higher education is also a responsibility that can be assumed by students with disabilities themselves.

Achieving inclusive education for students with disabilities requires that all HE role-players be willing to move out of their comfort zones and honour not only their conventional, but also additional, re-imagined responsibilities. DUSMs, lecturers, HEI leadership, and management and students with disabilities all have (varying) responsibilities when it comes to achieving inclusive education. Rather than looking for opportunities to shift our responsibilities onto one another, we need actively to find ways of sharing responsibilities and helping one another to do a better job of making genuine inclusivity our everyday taken-for-granted practice.

The present study was not without limitations. DUSMs constitute only one of the groups of relevant stakeholders whose cooperation is needed if we are to achieve inclusive education in South African higher education. Further research is needed to examine more closely what it would mean to 'move out of their comfort zones' from the perspective of other stakeholders such as lecturers, students with disabilities, and university management personnel.

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# CHAPTER 12

# POLICY, PRACTICE AND RESEARCH—MAKING THE CIRCLE BIGGER: CONCLUSIONS AND RECOMMENDATIONS

Desire Chiwandire and Louise Vincent

> *Epigraph>Although student support services play a crucial role in supporting students with disabilities, the entire institution and university population, staff and students alike, are responsible for creating an inclusive environment where students with disabilities can experience a sense of community and attitudes of embracing diversity and accommodating differences (Naidoo 2010, 6).*

This book has benefited immensely from contributions from a range of researchers from diverse disciplines. We want to end by saying a bit more about what we mean by ‘making the circle bigger’—a concept which we believe can help all role-players to promote inclusivity for students with disabilities at South African HEIs. In advancing this idea, we draw on the inclusive education literature both in South African and international contexts. In these final remarks we also draw from recommendations provided by our chapter contributors. Making ‘the circle bigger’, as suggested by Mutanga, requires Disability Studies researchers, particularly those researching issues of disability in higher education, to move away from traditional methodologies and to opt for approaches aimed at empowering students with disabilities. In his chapter, Mutanga models this approach by employing cognitive interviews—an approach which tries to avoid researchers from running the risk of using students with disabilities as tools in a research agenda which the participants themselves are not in a position to shape or direct.

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idea, we draw on the inclusive education literature both in South African and international contexts. In these final remarks we also draw from recommendations provided by our chapter contributors. Making 'the circle bigger', as suggested by Mutanga, requires Disability Studies researchers, particularly those researching issues of disability in higher education, to move away from traditional methodologies and to opt for approaches aimed at empowering students with disabilities. In his chapter, Mutanga models this approach by employing cognitive interviews—an approach which tries to avoid researchers from running the risk of using students with disabilities as tools in a research agenda which the participants themselves are not in a position to shape or direct.

Within research ethics, persons with disabilities are also considered to be a 'vulnerable group' (Padgett 2008). According to Domańska (2018, 2) a 'vulnerable group' 'is made up of individuals who particularly frequently experience unequal treatment'. This often negatively results in this groups' rights being 'limited and stratified by the social majority controlling the decision-making processes in the society' (Domańska 2018, 2). Mutanga's chapter shows us that Disability Studies researchers are also part of the social majority who control decision making, especially in relation to conducting research involving the inclusion of students with disabilities in South African HE. Hence, achieving social justice for students with disabilities requires South African Disability Studies scholars to comply with international, national, and university research ethics codes, most of which emphasise the need for researchers to respect their participants' human dignity. This is particularly important in the South African HE context, especially given the fact that students with disabilities have been, and continue to be, one of the most underrepresented groups in these institutions (Mutanga 2019).

Researchers seeking to understand the situation of students with disabilities in South African HEIs have tended to employ a narrow range of data generation methods—mainly qualitative, face-to face interviews and focus groups. We argue that this narrows the circle of understanding and restricts potentially rich avenues of interpretation and analysis. Chiwandire and Vincent's chapter on disability funding in HE points to the potential for document analysis and comparative approaches to yield useful information and insight to guide future policies and practices in issues related to disability funding in HE in Global North and Global South countries.

Re-evaluation of participation in, as well as the purposes, content and outcomes of, HE are currently burning issues both in South Africa and internationally. As former University of the Free State Vice- Chancellor Jonathan Jansen has argued, HE funding is one of the areas which needs immediate attention given that HEIs have experienced a dramatic decline in government subsidies and increases in student fees since the beginning of the millennium (Jansen 2017, 40). This narrowing of funding opportunities has disproportionately affected students with disabilities. In light of this, Letseka and Ngubane-Mokiwa propose that well-supported and implemented ODL could provide viable learning opportunities for students with disabilities, with tuition in institutions which provide ODL being expensive in comparison to full-time contact universities. Rather than bemoaning lack of funding as inevitably leading to fewer opportunities for participation for students with disabilities, making the circle bigger could mean looking to alternative models for quality education.

The field of Disability Studies has been criticised for favouring voices from the Global North at the expense of those from the Global South—thus marginalising the experiences of persons with disabilities living in Global South countries (Mallett and Runswick-Cole 2014; Meekosha 2008; Meekosha 2011). Another way in which we have tried to think about 'making the circle bigger' in this book is by suggesting (and modelling) the importance of utilising timely theoretical frameworks which are contextually relevant—in this case to the South African HE context. Ndlovu's chapter is a case in point—deploying de-colonial theory as a theoretical lens to explain the experiences of students with disabilities in relation to obstacles to their wellbeing across three professional programmes. In this chapter, Ndlovu widens the circle of Disability Studies by offering a Global South perspective which has, to date, been largely absent in this field.

Recent years has seen several South African scholars (see for example Walker and Unterhalter 2007; Wilson-Strydom 2011; Mutanga 2019) employing Sen's capabilities approach to analyse the current situation of students with disabilities in HEIs with the hope of widening access, and academic success' opportunities, for students with disabilities. Wilson-Strydom (2011, 408–409) proposes that 'the notion of capabilities provides a conceptual framework for exploring the complex processes underlying education outcomes in a manner that exposes injustices that are otherwise masked'. Likewise, Walker and Unterhalter (2007, 5) argue that 'the capability approach…offers a method to evaluate real educational advantage, and equally to identify disadvantage, marginalisation, and exclusion' in educational institutions. For these reasons, the capabilities approach can play an important role in 'understandings of individual wellbeing and social arrangements in a manner that explicitly supports a striving for just outcomes' (Wilson-Strydom 2011, 408–409).

Given that South African scholars who have used the capabilities approach have only used it to analyse issues of academic inclusion, and not non-academic issues or extracurricular activities, Moodley and Patsika's chapter is useful in addressing this gap through the Sen's capabilities approach to analyse whether or not one South African university provides equal opportunities for students with disabilities to participate in athletics. The chapter concluded that South African universities are still lagging behind in supporting students with disabilities to participate in sport, despite such opportunities being central in creating opportunities for growth and social interaction for these students. Likewise, previous South African studies (see Makiwane 2018; Chiwandire and Vincent 2017; Chiwandire 2021) have also confirmed that participation in sport at both competitive and recreational levels for students with disabilities has a positive impact on the social integration of students with disabilities, and also enhances the academic success of this group. Hence, achieving social justice for students with disabilities would require universities to remove all barriers restricting the full participation of students with disabilities in sport and recreational activities.

Another way in which the Disability Studies circle can be made bigger is in relation to who is given a voice in the field. In this book, for example, we hear the voices of DUSMs from various South African universities whose ideas about disability and inclusion in HE have previously seldom been heard. Chiwandire and Vincent's rationale for interviewing DUSMs stems from a call from former Higher Education Minister Blade Nzimande (cited in Pretorius et al. 2011, 2) at the 2010 Higher and Further Education Disability Services Association (HEDSA) symposium where he stated that:

> for far too long, disability issues have surfaced in our national and institutional policy documents and plans without meaningful action being taken to address the challenges which exist...Disability Units at the HEIs can and should play an important role in ensuring fair and equitable policies and practices for students with disabilities.

Chiwandire and Vincent's responsibility-sharing chapter questions whether DUSMs are fully meeting the learning needs of students. Through a critical approach, the chapter calls on DUSMs to move out of their comfort zones and to begin to do more than is traditionally expected by their profession if they are to support students with disabilities in a meaningful manner. This widening of our understanding of the responsibilities of these Disability Units then becomes another way in which the idea of widening the circle is relevant.

While some scholars have emphasised the need for the challenges facing students with disabilities in South Africa to be addressed in context, Peters et al. (2005, 140) have cautioned that 'local priorities and conditions may, and some-times do, contradict basic human rights and universal access to education'. What this means is that while staff members who have the responsibility of promoting the rights of students with disabilities in HEIs need to be sensitised to local conditions and needs, an awareness of best international practices on inclusive education is also critical. While these best practices stem from Global North countries, because these countries initiated the facilitation of students with disabilities in mainstream education much earlier than their Global South counterparts through enacting anti-discrimination legislation, this does not make these practices inherently irrelevant. Rather, it is our argument, the circle of our understanding of local conditions and priorities needs to be widened to include introspection and critique from the vantage point of knowledge of international practices and approaches.

In this book, we have also attempted to 'widen the circle' by broadening our understanding of the concept of inclusive education. To date, this concept has mainly been understood from an academic inclusion point of view: an emphasis on 'how disabled students experience teaching, learning and assessment in higher education' (Fuller et al. 2004, 306). This approach, for example, focuses on how lecturers design and teach flexible and accessible curricula which address the diverse needs of students including those with disabilities (see Howell 2015). However, our argument has been that this is a narrow approach to the idea of inclusive education which needs to be widened to encompass the social needs of students with disabilities as an essential step towards achieving meaningful recognition and acceptance and a sense of belonging on the part of students with disabilities on campuses (Robo 2014).

So, we see, for example, chapters in the book focusing on the participation of students with disabilities in sport as one aspect of social inclusion—a goal which is articulated in the *2012 White Paper on Sport and Recreation* calling for the establishment of mechanisms to assist talented people, including those with disabilities, to reach their full potential (Department of Sport and Recreation 2012). This widened approach to inclusion is seen in Article 30 of the UNCRPD as well, which provides for the participation of persons with disabilities in cultural life, recreation, leisure, and sport, and obliges signatories to take appropriate measures 'to ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources' (United Nations 2006, 23).

Apart from participation in sports and exercise as a right, proponents have noted that participation in sport for persons with disabilities has numerous benefits, such as improved health (Bohnert 2016) and mental wellbeing (Fox 1992 see also Jones 1995), reduction in the risk for chronic illnesses for persons with disabilities (Durstine et al. 2000; Heath and Fentem 1997), lower levels of anxiety and decreased stress (Martin 2006; Kristen et al. 2003; CDC 1997), lower instances of obesity (Bukhala 2009; Rimmer and Rowland 2007), reduced dependency on pain and depression medication (Dada and Ukpata 2017), as well as improved blood circulation, strengthened muscles, better balance and co-ordination (Rohwer 2013).

At an individual level, persons with disabilities who engage in sports and other social activities have improved peer relations and increased social interactions in comparison to those who do not engage in these activities (Blinde and McClung 1997; Shapiro and Martin 2010; DePauw 1992). For all these reasons, and many others, the circle of inclusion for students with disabilities should never be restricted to a narrow academic interpretation, but needs, critically, to be widened to incorporate social inclusion into diverse opportunities for full and equal participation in university life. When students with disabilities form more fully a part of social and recreational activities on campus, the often narrow understanding that non-disabled people have of persons with disabilities is also challenged: 'sports changes community perceptions of person with disabilities by focusing attention on their abilities and moving their disability into the background' (Dada and Ukpata 2017, 138–139; see also Losch 2015; Sherrill 2004). In this way, narrow perceptions focusing on disability can be widened so that the person can be seen and recognised (Dada and Ukpata 2017), challenging prejudice and stigmatisation. It has also been suggested that inclusion in a wider ambit of social activities has the potential to change what persons with disabilities think and feel about themselves in ways that are potentially empowering, and help individuals to recognise their own potential (Dada and Ukpata 2017).

In this book we have also attempted to 'widen the circle' by broadening our understanding of the concept of inclusive education through highlighting the potential positive role played by family members, especially parents, in creating more positive learning outcomes for students with disabilities in South African HEIs. The students with disabilities who participated in Moodley and Patsika's study is a case in point, as they acknowledged the positive impact of their family's support to their academic success. Recent studies into the experiences of students with disabilities have shown how a number of the participants have also appreciated the supportive role of their family members, especially their parents, for providing emotional support to them during difficult times in their studies (see, for instance, Phatoli et al. 2015; Mutanga 2019; Duma and Shawa 2019; Mutanga 2015). This shows that achieving the goals of inclusive education also requires the active participation of parents and other family members of students with disabilities.

The notion of social justice, as espoused by Rawls (1971), emphasises the distribution of material and non-material goods among members of a society as one of the ways of achieving equality. Within this distributive paradigm, social justice is defined 'as the morally proper distribution of social benefits and burdens among society's members' (Young 1990, 15). As identified in Chiwandire and Vincent's chapter on disability funding in HE, the inadequacy of NSFAS bursaries in meeting the day-to-day costs that arise as a result of students' disability is making it impossible for most South African HEIs to realise the goals of inclusive education for their students with disabilities in a meaningful manner. This has also been confirmed in recent numerous South African studies which indicate that funding for students with disabilities in HE continues not being a priority of government policy and expenditure (Simui et al. 2019; Mbuvha 2019; Ramaahlo et al. 2018). In this regard, from the ideals of social justice standpoint, 'making the circle bigger' will require the transformation of the educational system not only to focus on providing students with disabilities with access to HE opportunities, but most importantly, with opportunities to participate with success at these institutions. Hence, we agree with South African proponents of inclusive education that this will require the country's universities to ensure that 'sufficient funding, budgeting processes and commitment from senior management in the allocation of funding be secured' if these institutions are to widen access and participation with success opportunities for diverse students with disabilities (Ramaahlo et al. 2018, 367). It is our hope that the sufficient budget allocation for universities will help these institutions to address other barriers to academic and social inclusion for students with disabilities which were identified by other contributors in this book, most of which could be attributed to the lack of disability funding.

Making the circle bigger also means challenging the idea of treating students with disabilities as a homogenous group—a prejudice which results in overlooking the varied experiences of students with disabilities (Mutanga and Walker 2017). Treating students with disabilities as a homogenous group can result in lecturers adopting a one-size-fits-all approach to curriculum design which puts students with disabilities at an educational disadvantage, and contravenes the provisions of *White Paper 6* which state that 'new curriculum and assessment initiatives will be required to focus on the inclusion of the full range of diverse learning needs' (Department of Education 2001, 31-32). In order to address the diverse learning needs of students with disabilities, widening the circle requires curriculum differentiation as a central method of ensuring access (Department of Education Directorate: Inclusive Education 2005).

Thus, widening the access circle requires of lecturers, as Tomlinson (2000) has argued, efforts to respond to variance among students in the classroom through diversification of teaching and assessment modes and styles in order to create the best learning experience possible for students whose needs are very diverse. In order to do this, lecturers are themselves required to make the circle of their own skill set and the approaches to teaching and learning that they are comfortable with, bigger, and to move beyond the skills and knowledge 'traditionally required by the profession' (Mukhopadhyay et al. 2009, 51). Doing so would create inclusive universities where the barriers that students with disabilities with diverse needs encounter in teaching, learning and assessment are reduced (Fuller et al. 2004). In this regard, we advocate learning from best practices in countries like Australia where government has a code of practice document in place which obliges HEIs to put appropriate training programmes for staff in place to be able to respond effectively to the teaching and learning needs of students with disabilities (O'Connor et al. 1998).

All South African universities claim to comply with national disability policies. However, there are huge discrepancies in the ways in which individual universities support the learning and social inclusion needs of their students with disabilities. While some universities have more financial, human and infrastructural resources to support students with disabilities, others, particularly those located in rural settings and universities of technologies, are less resourced. Often a lack of resources is a significant barrier to translating policy into practice. While monitoring mechanisms ought to be put in place by the Department of Higher Education and Training (DHET) to ensure that all universities comply with the international- and national standards regarding the inclusion of students with disabilities, these mechanisms need to go along with additional funding, especially for universities which are lagging behind with regard to supporting students with disabilities.

'Making the circle bigger' requires South African HEIs to regard the disability movement slogan 'Nothing about us without us' seriously, which is to say that students with disabilities should not only be consulted, but also 'be actively involved in planning, creating or changing all aspects of our society' (Chard and Couch 1998, 605). Several studies have indicated that the continual underrepresentation and marginalisation of students with disabilities in HEIs stem primarily from these institutions' reluctance to consult with students with disabilities when it comes to the development of disability policy guidelines and practices (Moswela and Mukhopadhyay 2011; Vickerman and Blundell 2010). While the literature recommends the need to consult with students with disabilities, as several contributions have demonstrated, in reality, universities seldom consult with students with disabilities when it comes to addressing the challenges faced by this group. We propose the need for students with disabilities themselves to take the initiative—to develop self-advocacy skills—and to put these into practice in challenging their exclusion from policy making and implementation platforms and processes at their universities.

It is widely accepted that self-advocacy is one important way in which the voices of persons with disabilities can be heard and respected (Inclusion International 2016). Van Jaarsveldt and colleagues' chapter, which draws on the experiences of a blind student, Louzanne, who played an important role while she was on the SRC in sensitising her university's non-disabled community, including members of the university rectorate, speaks to the power of this approach. In this sense the book is of the opinion that students with disabilities also have a responsibility for 'making the circle bigger' for themselves. In doing so we are challenging portrayals of the HE environment as inherently disabling and therefore in need of change before students with disabilities can become effective and powerfully included voices on our campuses. Instead, our argument is that students with disabilities also have a responsibility to move out of their comfort zone and to take proactive measures to ensure that the higher education environment becomes disability friendly. In order to achieve this, students with disabilities need to develop self-advocacy skills that enable them to state and negotiate their individualised needs in educational settings, thus resulting in their full inclusion and participation. The very last word goes to one of the DUSMs interviewed in Chiwandire and Vincent's study:

> The bottom line, I think, is really to create what we call a sense of belonging, you know, for all students not to feel that there is pity on you. Students should feel that 'definitely, here I belong', you know, 'I don't feel that I'm being marginalised, or I'm being tolerated'. So that, to me, are fundamental issues around inclusion in our higher education environment (Mpendulo).

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