

‘Nothing for us without us’: Exclusion of students with disabilities in disability policy review at a South African institution of higher education

Sibonokuhle Ndlovu & Emmet Tadesse Woldegiorgis

Ali Mazrui Centre, University of Johannesburg
South Africa.

Abstract

The prominent disability rights slogan ‘nothing for us without us’ which was adopted from the 16th-century Polish revolution ‘nihil de nobis, sine nobis’, means that persons with disabilities, should be involved in anything that concerns their welfare so that they speak for themselves as people with a lived experience of disabilities. This empirical paper explores the participation of students with disabilities in the review of an institutional disability policy in a single institution of higher education in South Africa. Qualitative data were collected through interviews with twelve students with disabilities and seven disability unit staff members. Informed by critical disability theory, the finding was that there was limited participation by students with disabilities in the formulation of institutional disability policy meant for their welfare. While contemporary scholarship on disability seeks to address the exclusion of historically disadvantaged social groups such as those with disabilities but without privileging the voice of those with a lived experience of disability in policy issues, the ‘nothing for us without us’ slogan will remain elusive, fragile and cliché merely chanted. The paper thus aims to contribute to the understanding that limited participation in policy formulation could negatively affect the learning of students with disabilities and consequently their timely graduation. For genuine inclusion, all students, including those with disabilities will fully participate in higher learning.

Keywords: Students with disabilities, institutional disability policy, participation, South African higher education, inclusion, non-participation

Introduction

Participation in higher education by students from diverse groups is the goal and agenda of democratic countries at large, including the government of South Africa. South African higher education actors are making effort to ensure that all previously disadvantaged social groups—including students with disabilities—have the opportunity, not only to access higher education but to also fully participate in learning and succeed. For instance, the National Plan on Education in South Africa has advocated for an inclusive higher education and the enrolment of diverse students, including those with disabilities and access have since broadened. It is the role of the responsible stakeholders in higher education to drive the inclusion of all students, including those with disabilities, using the relevant policy frameworks. It is imperative to also advocate for a participatory shift in educational policy in South Africa to create a space accommodating the voices of stakeholders across the spectrum of different academic programmes.

The problem identified in the paper is that while it is expected that students with disabilities learn and succeed like all other students in higher education, their exclusion starts at the very outset—namely, in their non-involvement in policy. Inclusiveness in higher education rightly advocates for the participation of students with disabilities and those categorised as having ‘special educational needs’. Nevertheless, inclusiveness must start with decision-making that accommodates the voices of disabled people in designing policies and strategies that overcome all barriers to equal participation in higher education. Unfortunately, the lived experiences and voices of disabled people have not been at the heart of policymaking in higher education. Often, institutional disability policies in higher education consider only quantitative or statistical data to inform their decision-making processes. Such data is often incomplete and does not reflect the complexity of the well-being of disabled people and their actual daily experiences. It is critical to reflect on the question of how we can enhance the role of students with disability in policy processes, and how higher education institutions will change the status quo. It is thus paramount to articulate the challenges that blocked the voices of students with disability in institutional disability policy processes.

The argument in this study is that while South African higher education is said to have the most comprehensive policies addressing disability among all African countries, there is the exclusion of those for whom the policy is intended. Students with disabilities have particularly limited participation and are not actively involved in policy issues that inform their welfare.

When the involvement and participation of students with disabilities in their own welfare and affairs is a mere slogan, adverse repercussions on their academic performance can be expected.

International classification of functioning, disability, and health

Several international studies have sought to understand participation of children and youth with disabilities in education as explained in the World Health Organization (WHO) International Classification of Functioning (ICF), Disability and Health (2001). This instrument conceptualises participation in ways that could help to inform policy, research and inclusion. The ICF definition of *participation* refers to a ‘person’s involvement in a life situation’ (WHO, 2001, p. 213). *Participation* also refers to involvement in an activity (Maxwell, Grandlund & Augustine, 2018). In both definitions, the denominator is that there has to be some involvement when one is participating, with involvement being defined as ‘taking part, being included or engaged in an area of life, being accepted or having access to needed resources’ (WHO, 2001, p. 15). The key common requirements in the two definitions are that there has to be a life situation, an event or an activity, and then an involvement, in which an individual is taking part. The ICF meaning of participation, therefore, refers to an inclusive context, in which an individual is involved in activities or life situations within a specific environment. It could be argued that both a conducive environment and the individual’s involvement are necessary variables for participation to take place. On the one hand, the activity or life situation within the environment should be conducive and the individual should be involved. Non-participation, on the other hand, would be a situation where there is no involvement by an individual in an activity or life situation within a specific environment.

The level of participation can also be determined in the ICF context. It is determined by measuring the extent to which an individual is involved in an activity or life situation. The level of involvement, which equals the participation level, is determined by measuring the frequency of attendance or the intensity of engagement. As Maxwell et al. (2018) explained, ‘A viable way of assessing the involvement of a person in their environment is to measure either the frequency of attendance or the intensity of engagement in a life situation’ (p. 48). They argued that this could be measured either from the sociological or psychological perspective. From the sociological perspective, the focus is on the availability of activities in the environment and participation is the frequency of having access to the activities and attending them. This implies that the extent to which an individual has access to the activities in the environment and the frequency of attending them, determine the level of participation for the individual. It could be argued that the more the individual has access to the activities

and the more he or she attends them, the higher the probability of a higher level of participation. This perspective seems to emphasise that the environment should be accommodative if an individual has to be involved frequently. It could be argued, however, that having access alone is not enough as an individual could have access but for some reason, their frequency of attendance is low. The individual's frequency of attendance of an activity could be seen as being more important for determining the level of involvement, and consequently their level of participation.

There are different debates about using ICF for understanding participation, and the common assumption is that it is limited in several respects. Lack of clarity about the definition of *life situations* is a major source of ambiguity about the boundaries between activity and participation. Although the definition of activity appears quite specific (i.e., execution of a task or action), it is not clear at what point a 'task' becomes a 'life situation'. Existing measures have limitations in content, feasibility or breadth that limit their application across diverse populations and research contexts (McConachie et al., 2006).

Granlund (2013) argued strongly against the exclusion of the subjective component from the ICF model. His position is that the subjective aspect of participation is crucial for understanding the person's situation and must also be a focus of measurement. Reliance on observations as indicators of participation has been criticised as being based on a false assumption, namely that what is observed reflects the person's actual experience ([Moretti et al., 2012](#)). Thus, it is argued, a person may look uninvolved to an observer but may experience themselves as very uninvolved in a situation. For example, children often participate in family social events by observing and listening while practically they are seen as not participating.

Conscious of the limitation of the ICF framework in understanding participation, the 2018 study by Maxwell et al. used a newly revised version of the ICF, referred to as ICF-2. The latter version captures 'the involvement experience of the individual' postulated in WHO (2018, p. 2), thus enabling a more useful classification framework, as the level of participation can be measured within the context of inclusive education. The authors added that 'the concept of involvement should also consider the sense of belonging. This implies that where there is full participation, an individual should feel that he or she belongs. One would not understand participation without getting the experience directly from persons with a lived experience. In this study, perception, experiences and utterances of students with disabilities themselves were thus very important in understanding their participation in specific policy making at the institution.

Level of participation from the psychological perspective

The psychological perspective focuses on the environment being accommodative and that the individual persons with disabilities accept the environmental context as conducive to their needs. It assumes that the level of acceptance determines the level of intensity of involvement in an activity or not. Here, it implies that the level of participation is determined by the individual’s acceptance of the activity in the environment and the frequency of attendance to the activity. It could be argued that high participation occurs when all three elements (the environment, acceptance of activity, and intensity of involvement) combine well. The psychological perspective thus seems to be focused on the interplay of an accommodative environment, the individual’s acceptance of the activity within the environment, and the frequency of attendance to the activity.

An individual plays an important role in the level at which he or she participates in an activity. Here, it implies that it is the individual who determines the intensity of involvement by accepting both the environment and the activity. Thus, while a conducive environment also plays an important role in determining the level of participation, the individual’s acceptance of the activity in the environment and the intensity of involvement are an individual’s choice. In other words, even if the environment may not be accommodative, getting involved in the activity, and participating intensively, remains the choice of the individual. It could be argued that whether the environment and activity are accommodative or not, the choice is still in the individual’s court to be involved intensively or not. It is what will determine the level at which they participate. In essence, that the environment is accommodative, may not determine the frequency of attendance and involvement by the individual and vice versa. Understanding the level of participation and how it is determined was important for this study, as it helped to inform the understanding of the level of stakeholders’ participation in the institutional disability policy in the specific institution.

Participation in the South African context

Howell (2005) argued that creating equity for students with disabilities requires that attention be focused on their participation within the system. He thus understands the participation of students with disabilities in terms of equity. It suggests that for him that when students with disabilities are also represented, they are participating. Goode (2007) observed that when students with disabilities are not fully participating, they disappear from view and become ‘invisible’. It suggests for Goode that participation involves active involvement and been visible. In this study, we hold a different view from Goode. We argue that students with

disabilities can fully participate while they are not visible because participation can either be active and observable or non-active and dormant. This is why participation can only be fully understood from the lived experiences of the actors, which is the case in the present study where the utterances of students with disabilities were of prime importance. Hugo (2012) argued that the level of participation might help to understand whether or not students with disabilities are fully included or are only integrated. Integration means that students with disabilities are only accepted into the system but are not included in it. The experiences of participation or non-participation were thus important as they broadly inform whether or not students with disabilities were included at the specific institution as the issue of participation is inextricably intertwined and inseparable from the inclusion of all diversity: the subject of great interest in contemporary scholarship.

Disability policies in South African higher education

Among African countries, South Africa has the most comprehensive policies of inclusion (Chataika, 2007). In South Africa, the Constitution (Republic of South Africa, 1996), policies of inclusion, and institutional disability policies, are very important for students with disabilities as these policies inform how they are included in higher education and disability policies in each individual learning space. The policy best geared for inclusion from basic education to higher education is the Education White Paper 6 (EWP6): Special Needs Education: Building an Inclusive Education and Training System (DoE, 2001).

In 2018, the Post-School Education and Training (PSET) strategic disability policy was enacted (PSET, 2018), its purpose being:

....to create an inclusive PSET system for people with disabilities, guide PSET institutions in the creation of an enabling environment for people with disabilities; and provide the DHET with a monitoring and evaluation instrument to ensure that disability compliance is mainstreamed in all PSET institutions (p. 15).

Thus the policy clearly outlines and demands that a conducive environment be created by all institutions of higher education for the participation of students with disabilities. This should especially include in policy making, which is a starting point for inclusion.

The institutional disability policy in South African higher education

In pursuit of the inclusion of students with disabilities, South Africa's institutions of higher education have also developed internal institutional disability policies. Nine historical advantaged institutions out of the 26 public Higher Education institutions have institutional disability policies (Matshedisho, 2007). The specific institution of focus was one of those with

a formal institutional disability policy at the time. Matshediso (2007) reported that limited funding prevents some institutions from having such internal policies. As a result, some institutions do not provide disability support and have no disability rights units. The institutional disability policy provides a framework for how students with disabilities will be included at a specific institution.

The focus of this study is one of the few that have an institutional disability policy that serves the welfare of those it is meant for. It would be expected that students with disabilities fully participate in the formulation, review and implementation of the policy. Otherwise, without the participation of those served by the policy, this remains on paper and does not enable changes for marginalised people with disabilities.

Key questions for the study

- a) How are students with disabilities limited in participating in the institutional disability policy at the specific South African institutions?
- b) How can South Africa’s institutions of higher education employ the insights and challenges placed before them by student voices, to rethink policy so that it serves the needs of those for whom it is intended?
- c) How can the ‘nothing for us without us’ slogan be used for collective responsibility and joint accountability by students with disabilities in policy issues?
- d) What would participation in policy do that would not only facilitate inclusion of students with disabilities but also provide the mechanisms to continuously renegotiate the terms of inclusion and recognition as ways to disrupt the exclusive frames imposed on them?

The paper analysed the lived experiences of students with disabilities in terms of their level of participation in institutional disability policy. It also addressed the question of how limited participation in policy could harm their learning. Finally, the paper considered how the slogan of ‘nothing for us, without us’ could be made real by utilising the views of students with disabilities, in terms of being involved in policy matters, as the way forward.

Critical Disability Studies as a framework

Critical Disability Studies (CDS) critique the social norms and cultural constructions of disability, thereby contesting the societal barriers that produce stigma and marginalisation of persons with disabilities. CDS considers disability as socially constructed through the material and local contextual conditions that influence the social practices, policies, and social and

physical structures that marginalises persons with disabilities (Meekosha & Shuttleworth, 2009).

The relevance of CDS as a framework for this paper is its demand that scholars in the field work toward universal accessibility of all diverse people since scholars' concern for those with disabilities is that they are often marginalised and excluded in many contexts. Thus CDS prioritises the lived realities of people with disabilities and values their participation in interpreting their own space in the world (Meekosha & Shuttleworth, 2009). They contest the barriers imposed on those with disability by society, and that limit their access to education, employment, transportation and a host of public and private services.

In CDS, hidden oppressive societal power relations in specific contexts are viewed as the underlying cause for the exclusion of persons with disabilities, thereby denying them participation, accommodation and the equality of life they also deserve in all areas of life. It is in this regard—that power dynamics are oppressive in specific contexts—is their concern. Thus, where policy participation by students with disability is involved, specific theoretical concepts from CDS provide useful lenses in terms of understanding the deeper underlying explanation of their level of participation.

Analysis by CDS of the specific elements of unequal power dynamics in different contexts of higher education and the universalisation of the human rights discourse deriving from *The United Nations Convention on the Rights of People with Disabilities* (UNCRPD) help to illuminate the exclusion of students with disabilities in policy participation. It enables a holistic analysis of the social, cultural, and physical conditions influencing the exclusions of persons with disabilities in society at large and in institutions such as those of higher education.

Power dynamics in the Global South

Meekosha & Soldatic (2011) argue that the hegemonic North determines the constitution of human rights but overlooks the power imbalances embedded in the hierarchical systems in the Global South. It means that power dynamics and hierarchy that exist in social institutions and that have implications for human rights are taken for granted. It could be argued, therefore, that even though the human rights discourse has been accepted in African countries, maintenance of unequal power dynamics could be seen as a subtle continuation of colonialism. Those who have power may still violate the rights of the powerless and vulnerable such as those with disabilities, despite them having the same human rights as other people. It is thus argued that in the Global South, 'Human rights violations are not accidents...' but are '... rather, symptoms

of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm’ (Farmer, 2005, p. 7). Those who suffer abuse are those placed in the lower hierarchy of the power structure while those positioned in the higher hierarchies (i.e., without disabilities) are shielded from the oppression resulting from power dynamics; they hence are powerful. In essence, violation of human rights in the case of participation of the powerless, such as those with disabilities, is highly likely. Understanding the power dynamics in a particular school context in South Africa, could thus assist in explaining the level of participation in institutional disability policy review by students with disabilities.

The universalisation of the human rights discourse

CDS scholars start broadly by critiquing the international legal instrument, *The United Nations Convention on the Rights of People with Disabilities* (UNCRPD). The UNCRPD addresses the inclusion of those with disabilities from the human rights perspective (Meekosha & Soldatic, 2011), highlighting that they have the right to be included/participate in issues that inform their welfare. The UNCRPD consideration of participation of people with disability as an individual right creates an expectation that full inclusion/participation by students with disabilities in policy aimed at their welfare would occur. However, CDS scholars critique this universalisation of the human rights discourse, considering it to stem from the great narrative of the Global North (Mutua, 2005; De Sousa Santos, 2008; Meekosha & Soldatic, 2011). They critique the UNCRPD generalisation of how human rights is constituted in in the North to other contexts, especially, to the Global South. In the context of some African institutions, some people are, unfortunately, treated as *more human* than others. Thus, responsible authorities in the Global South could on the one hand subscribe to human rights language and principles in theory, while they violate the human rights of individuals, on the other.

Furthermore, according to critical disability scholars the instrument may not assist the participation of students with disabilities because it frames disability as personal tragedy, resulting in activity limitation, rather than a form of social oppression that denies individuals citizenship and participation (Cobigo & Stuart, 2010). In contrast the CDS perspective, critique the medical model and social construction of disability. It is in that respect that the two elements were used to understand the participation of students with disabilities in policy review at the institution.

Method

Data for this study was obtained from nineteen participants by using a qualitative method. The participants included twelve students with disabilities and seven disability unit staff members. After obtaining their broad opinions using a survey questionnaire, they were interviewed in depth individually or in groups. The students with disabilities were enrolled in professional degrees at one institution of higher learning.

Sample and sampling procedure

Sampling was purposive, and a formerly advantaged institution with a long-established disability support structure since 1986 (from before independence) was selected. The institution supports 16 categories of disabilities, including learning disabilities which is not yet supported by other institutions (Ndlovu, 2017). It has greater support for disabilities than other institutions in the country. The institution even provided disability support to students with disabilities when they were at home during COVID-19 shutdown (Disability Rights Unit, 2020). As policy plays a major role in informing disability support, participation or otherwise in the institutional disability policy formulation by all stakeholders—including students with disabilities—could be determined at the institution.

Students with lived experience of disability and for whom institutional disability policy is meant to facilitate welfare were selected. They were drawn from three professional programmes, namely medicine, law and education. These belonged to three different faculties; health sciences, law and commerce, and humanities, respectively. The three programmes were thus representative of an institution that has five faculties. Fourteen students from the three faculties volunteered to participate. The sample comprised undergraduate and postgraduate students, with the undergraduates been in their final year of study; participants were therefore expected to be conversant with policy issues at the institution. The sample cut across race, gender, age, socioeconomic background and disability category. The disability categories included visual, hearing impairments, physical disabilities and albinism. The age range was from 18 to 35.

The staff members from the university's Disability Resource Centre were selected as the providers of disability support to those students, their provision guided by policy. It was also anticipated that these staff members would be participants in disability policy development and implementation at the institution. Seven of them volunteered to participate in the study. Three of them also had disabilities which included albinism, low vision and physical

disabilities. They were all permanent staff members, who had been at the Centre for a period ranging from ten to 25 years. Thus, the specific institution and the purposively selected participants were ideal for analysing the level of participation of students with disabilities in the institutional disability policy.

Data collection and data analysis

The qualitative questions of the survey were formulated to address the three broad questions of the study that were highlighted earlier on. The interview method was adopted as the data collection tool because it enabled depth and probing (Creswell, 2008). After data had been collected, thematic data analysis was employed to derive the categories that emerged from data from the perspectives of the individual participants and thereby summarising the key features of the collected data (Nowell et al., 2017; Saldana, 2014).

The thematic data analysis process was done in phases; the first was to familiarise the researcher with the data through prolonged engagement and label and number the data to generate the initial codes. This was followed by the researcher inferring the recurring patterns, which generated the minor themes. The latter were collapsed, abstracted for meaning and grouped into categories of major themes. The major themes were vetted and tested using the reflexive journaling (Nowell et al., 2017; Saldana, 2014). The process involved returning to the raw data repeatedly for comparison. Checking with members and peer debriefing was used to establish trustworthiness and lastly the categories were matched and confirmed.

Ethical considerations

All ethical procedures and protocols were followed for confidentiality, anonymity, and privacy. It was confirmed for participants that their involvement was voluntary and that they had the right to withdraw from the study; consent was sought and obtained from all participants, before the start of data collection. The ethics clearance certificate 2013ECE106 was issued by the relevant ethics committee at the institution.

Results

Review of institutional disability policy at the institution

At the time the study was conducted, the institutional disability policy had just been reviewed and a new policy had been developed based on the review. All seven members of the Disability Rights Centre stated that the new policy has since been approved. There had previously been a single policy for both students and staff members, whereas separate components for students

and staff had been developed in the new policy. The members stated that the revised policy now catered for new categories of disability that had emerged and unclear aspects of the previous policy had been made clearer. They confirmed that the new disability policy, had two parts, one specifically for students with disabilities and another for staff members with disabilities. For students, the policy now covered substantial content on accommodations for disabilities. The review process and drafting of the new disability policy were carried out by specific members of the disability unit staff, some representatives of the transformation committee and representatives of higher authorities at the institution.

One of the participating staff stated: ‘Well we have recently worked on a new disability version and it’s available to all staff members’. Another staff member viewed the revised policy as an advance on the previous one, saying: ‘Actually, we have improved it recently. It’s a brand new policy and has been approved from last year’. From the statement uttered, the new version of the policy had been made available to all staff members but no mention was made of it being made available to students with disabilities.

Describing the involvement of the other stakeholders in the process, another staff member said:

We didn’t do the policy alone; it was done in collaboration with the transformation office who deals mostly on staff issues on gender and disability issue. The policy is now more accommodative to other new diversities that are coming through. We also adjusted it according to resources we are using presently. There was a lot that needed to be adjusted.

Considering the ‘nothing for us, without us’ mantra, it is natural to expect that students with disabilities participated in all processes and decision-making when the review of policy was done and a new institutional disability policy was developed at the institutional level. However, there was a gap, in that no mention was made of participation by students in either the policy review process or the development of a new institutional policy.

Invitation of students with disabilities for review of policy

Out of the twelve students with disabilities - spanning gender, race, age and disability categories, ten stated that they were not invited to the review of the existing policy and drafting of the new one. They confirmed that they did not even know there was a new disability policy for them at the institution. One of them stated: ‘Truly speaking, I don’t even know there is a new disability policy. I don’t know what you are talking about’. Another one stated: ‘Not me,

I didn’t hear about it, even from friends!’ Another echoed the same that he was not aware of the policy issue:

I would not want to lie; I am very ignorant in that area. I don’t even know there is a new policy and what it is all about. No, I wasn’t invited, maybe it was there somewhere, I did not read it, but I am not aware.

All ten students who were not invited to participate in the making of the new policy expressed the view that they were disgruntled about their lack of participation. They stressed that they should have been consulted or invited to a meeting because the institutional disability policy is for them. One student suggested that even a survey would have sufficed; they should have been allowed the opportunity to complete a survey and share their views. In one of their statements, one student stated:

I think it would be a courtesy for them to communicate to us about the policy because it is the policy for disabled persons. It doesn’t make sense where you would make a policy for disabled students and they are not involved.

From the sample of students with disabilities interviewed, it is clear that most of them did not even know that there was a new institutional disability policy. We thus argue that the participation level of students with disabilities concerning the policy was low.

Overlooking diversity in participation in the institutional disability policy

The diversity of students’ disabilities might have been overlooked when inviting them to participate in the meeting for institutional disability policy review, and the development of the new policy. This omission was seen when invitations were sent to selected students and not disability categories of students were represented. It emerged that despite the majority of the students with disabilities not knowing about the new policy and not having participated in its review, two of them were aware. One said he knew about the issue of the new policy development but that he was also not invited to participate. He was a postgraduate student who was also a staff member. He reported, ‘The information was sent to me. The staff has access to it on their computers. They will say, ‘Staff have a look at this! That’s how I got it.’

Another student with disabilities had a different experience from the others in terms of the specific policy. She stated that some students with disabilities were invited to the review process. ‘... an email was sent to a few of us, not everybody’. She further clarified that she attended the meeting on behalf of another student who could not be present because it coincided

with the latter's class. It was further revealed that the student who participated was on the Disability Committee. She said, 'I am in the disability awareness executive committee. I was invited because somebody else could not make it. And the timing as well! It was during class.'

We thus gathered from student interview that a few students, especially those in the Executive Committee for Disability, were invited to the policy meeting. However, even those who were invited to participate in the meeting were also dissatisfied with the time scheduled for the meeting because it did not suit them. The meeting was called during student lecture time. One student who would have attended, failed to do so because the time coincided with her lecture and she had to ask someone to attend on her behalf. Thus, though the responsible authorities might have intended that the student representatives with disabilities attend the meeting to represent their other disabled counterparts, they also unintentionally excluded them by way of inappropriate timing of the meeting for the institutional disability policy.

It could be argued that the responsible stakeholder might have thought that those few invitees would represent other students with disabilities. Though logical, nonetheless, representation by only a few students might not adequately represent the varied disability categories affected. Invitees in one category of disability might not know the learning needs of the others and how they should be catered for in teaching. Moreover, because of different social and educational backgrounds and orientations, persons of the same disability category could have different needs. Thus, though Howell (2006) views participation in terms of equity, we argue that one student out of twelve participating in a policy meeting is not representative and is inadequate. While the stakeholders' effort to invite some students via email is acknowledged and viewed in a positive light, it raises concerns about the inclusion of those students at the institution in general and about their participation levels specifically.

All ten students research participant with disabilities who did not participate in the policy meeting were dissatisfied. They expressed the view that participation by one student was not adequate representation. Their dissatisfaction was shown in one of the students with disabilities' statement that:

one student would not, of course, speak for all disabilities. At the end of the day he is disabled in his own way. He might not know how other people are feeling with their disabilities. That's why I am saying they should have called all of us so that even if we have grievances or questions, we would raise them there.

The statement above suggests that students with disabilities were willing to participate in the policy meeting but were constrained. Those with disabilities expected to be included and be allowed the opportunity to participate in the institutional disability meant for them. We recognise the exasperation of students with disabilities as justified when they were not invited to participate because there are generally few within the student body in higher learning (Fotim, 2011). They could have been invited to participate in the formulation of an institutional disability policy meant for their inclusion at the institution. Denying them participation in the development of policy meant for them was tantamount to the perpetuation of a practice that is highly contested in the disability field- in which those without disabilities speak for and make decisions for persons with disabilities who have a lived experience of disability (Titchkosky, 2003; Pothier & Devlin, 2006; Hosking, 2008). A picture of domination of those with disabilities by the able-bodied society is reflected in this specific social context.

Discussion

Limited participation in institutional disability policy at the institution

The study revealed that there was limited participation by students with disabilities either in the review process of the existing institutional disability policy or in the development of a new policy. Drawing from the definition of participation, the experience identified in the development of the policy in the current study involved low frequency, limited attendance in the activity, and an environment that was not fully conducive to enabling relevant student involvement (Maxwell, Grandlund & Augustine, 2018). The accounts of the interviewed students with disabilities with regards to their involvement in the institutional disability policy formulation at the institution meet the criteria of *limited participation*. Though there was some representation by one student who was invited to participate, the fact that the majority of the students with disabilities did not even know that disability policy issues were being discussed at the institution shows that the level of participation was lower than expected. In essence, students with disabilities did not engage fully in institutional policy design at the institution.

Top-down approaches to the review of policy

What the study reveals is a top-down approach to review policy were revealed at this institution. Ten out of the fourteen research participant students with disabilities did not participate in the disability policy review and development of the new one. It was the members of the Disability Unit, members of the Transformation Committee and only some students with disabilities, representing others, who participated. It has been argued that in the South African context,

when it comes to policy issues in general, the process has always been top-down, right from the national level. Thus the elite dominate the policy formulation terrain and the subjects for whom the policy is intended are excluded in the process. This has resulted in a policy disjuncture in which there are ‘beautiful’ policies on paper, but which are not fully implemented, and which do not address the welfare of those for whom they are intended. The current study confirms this as students with disabilities, at whom the institutional disability policy is aimed, are excluded, leaving only ‘experts’ to be determinant in the policy review and development of the new one.

Violation of individual rights owing to the existing power dynamics

Using the lens of CDS, limited participation by students with disabilities in the review of the old institutional disability policy, and the development of the new one, could be explained as a violation of the rights of students with disabilities owing to the inequitable power dynamics evident in the school. Farmer explained that ‘Human rights violations are not accidents....’ but are ‘... rather, symptoms of deeper pathologies of power... linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm’ (Farmer, 2005, p. 7). As students with disabilities were excluded from participation in the meeting for the policy review in the study, those who were victimized by the pathologies of power were those because they were placed at the low rung of the power hierarchy, while those shielded from harm were those who were located higher in that structure, who made decisions on institutional policy without involving those who the welfare policy was aimed at. It could be argued that the invisible underlying cause of the violation of individual rights of these students with disabilities is deeper than is seen at the surface level; hence, without addressing the inherent power dynamics, the human rights discourse will remain on paper and not be implemented.

From the CDS perspective, how the policy review process was handled could be explained in terms of social norms and cultural constructions of disability in the African context. Most African societies are socially gerontocratic and the elderly speaking for children and those without disabilities speaking for those with the disabilities is the norm. Authorities at the African institution of education were influenced by the way their society socially and culturally construct disability; hence they did not see any anomaly in speaking for students with disabilities in terms of policy review.

Because South Africa has ratified the UNCRPD one would expect responsible stakeholders to consider the full participation of students with disabilities in the institutional disability meeting as their individual right. However, owing to social norms and cultural constructions of disability in the African context, those placed higher in the hierarchy had and used the power to ‘speak on their behalf’ of others. Critical disability scholarship has revealed that speaking for those with disabilities, who have a lived experience of disability, by those without disability is an unfortunate but all too common phenomenon in society (Titchkosky, 2003; Hosking, 2008) as well as the application of top-down approaches to dealing with issues affecting people with disability (Pothier & Devlin, 2006). In this paper, this applies to the responsible authorities, namely the Disability Unit and Transformation members who made decisions for students with disabilities in respect of the institutional disability policy review. It speaks to universalisation of individual rights in the UNCRPD that clearly are never applied equally across all contexts, because rights are conceived differently.

A disability unit member’s statement that “. . . we have improved it [i.e., the policy] recently. It’s a brand new policy and has been approved from last year” suggests that they felt they had indeed improved the policy for students with disabilities. However, what the member considered improvement was not necessarily conceived as such by those with lived experience of disability. Thus, the ‘nothing for us without us’ mantra was violated as the “improvement” in the policy was assessed and accepted by others other than the students with disability themselves whose welfare the institutional disability policy was meant to inform.

Lack of understanding of the intersectionality of disability

The non-implementation of diversity when inviting students with disability to the meeting could be explained as due to a lack of understanding of intersectionality by the responsible authorities who were involved with the institutional disability policy review at the institution. Intersectionality of disabilities is one aspect that critical disability scholars emphasise since students with disabilities are not homogeneous. Hence there is a need to consider their diversities when making provisions for these students (Shildrick, 2012). A student in education explained why the consideration of diversity is an important element of intersectionality when he said:

When you interact with other disabled students, they will tell you it’s never enough. Whatever the institution does is never enough for us; it can only meet us halfway. It’s because of our individualistic needs, which are different and unique.

What I may find enough, the next person with the same disability as mine might find it not enough. When I say this is quite fine for me, the other person with the same disability will say not for me. So, there is no best universal system that can apply to everybody who is disabled. It's not a one size fit all kind of a thing.

The student speaks to the issue of the group and individual differences within disability, that each one of them should have been invited to a policy meeting for them to be able to speak for themselves as individuals with unique needs. It could be argued that it is when all unique needs are catered for in the institutional disability policy that students with disabilities could be said to be included, especially in terms of their learning needs. Young (1990) explained that it is reductionist to view subjects as a unit and to value commonness and sameness over difference. Social injustices and oppression arise when differences are overlooked. Students with disabilities themselves confirm that they are not homogeneous and thus cannot be represented by others in policy meetings. It is in this respect that we understand the united voice of all students with disabilities who were not invited to the meeting in their different disability categories that they should all have been invited to be involved in policies that concern their welfare.

Because individuals with disabilities have unique needs, all of them should have been invited to disability policy meetings. It is their individual right and if they are allowed the opportunity to speak for themselves, the 'nothing for us without us' slogan would be have been effected and not only remain a slogan. It could be argued that if students with disabilities fully participate in a policy meeting, it will in itself improve the new policy. While it is acknowledged that a collective voice could be listened to and responded to quicker, for individual/unique needs to be met, individuals should be empowered to speak for themselves and different voices be collated and summarised into needs that could be catered for in the institutional disability policy. At this specific institution, we argue for the possibility that the new policy is still exclusive in terms of the welfare of all different disability categories because students' needs might have not been fully represented by the few students who participated in the meeting.

Negative psychological impact

Limited participation in institutional disability has negative psychological implications for students with disabilities. From the psychological perspective, for intensive participation to occur, the environment needs to be accommodative, at the same time that the individual accepts

the activity and gets intensively involved (Maxwell et al., 2018). In this specific case, the environment did not accommodate the students’ intensive involvement even though students may have wanted to participate. Thus, isolation, discrimination and marginalisation limited participation and, based on information from the interview, subsequently harmed the psyche of the students with disabilities. Though the psychological impact could not be seen at the surface level, students themselves stated that being isolated, discriminated against and marginalised to the extent that they were not even invited to participate in a policy that is meant for their welfare, affected them psychologically. Thus, limited participation in the institutional disability policy process had a negative psychological impact on students with disabilities.

Negative effect on learning

The impact on the learning of students with disabilities could be explained as a ripple effect of the continued exclusion via limited participation in the institutional disability policy. Ndlovu (2017) revealed that at the specific institution under study, the general academic community did not attend the workshops organised by the Disability Rights Centre, which taught attendees about different categories of disabilities. This non-attendance by the general academic community was because participation was not compulsory. This suggests that it was not in the institutional disability policy that the general academic community attend these workshops. Had it been a policy issue, they would be bound by policy to attend those workshops. Such professional development workshops would clearly assist in the teaching and learning of students with disabilities at the institution.

Thus, not only did limited participation in the policy review harm the psyche of students with disabilities, it also impeded their learning. This was evidenced when a medical student stated: ‘Without emotional support or psychological support, you just fall off’. A disability staff member also confirmed, ‘If that person is not psychologically well, that person will not pass and get a degree’. Thus, while limited participation in policy could be seen as an issue outside the learning arena, it is actually intrinsically interlinked and interconnected to the psychological well-being and learning of students with disabilities.

‘Nothing for us without us’—Students’ voice as the way forward

The ‘nothing for us, without us’ mantra did not work for the students because the new institutional policy had been approved without them fully participating in the review of the previous policy and development of the new one. As a way forward, the researcher thus utilised

the voice of the students with disabilities in the study to suggest ways in which participation in the institutional disability policy could be enhanced.

Finally, the institutional disability policy may not be separate from students with disabilities' learning because if these students actively participate in the review process of the policy, they would have the opportunity for their voices to be heard. This applies to how they would want to be taught and how they learn. This would have allowed for their voices to be incorporated into the curriculum design, and in turn, the lecturers would be bound by policy to teach for different disability categories in ways that reflect the proposals by the students who themselves have the lived experience of disability. However, this could only be achieved where there is full participation in policy issues by students with disabilities and where the 'nothing for us, without us slogan' is implemented in practice—and not merely chanted in theory.

Conclusion

The paper discussed the non/participation of students with disabilities in an institutional disability policy review at an institution of higher education in South Africa. The analysis of accounts of the Disability Unit members, experiences of students with disabilities, and their perceptions of their participation in institutional disability policy formulation were analysed. The finding of the study is that students with disabilities' participation in policy issues at the institution was limited, which in turn negatively impacted their psyches and learning. The slogan of 'nothing for us, without us' was thus seen to ring hollow in a situation where students with disabilities did not fully participate in the institutional disability policy that was meant to have influenced and facilitated their welfare broadly and their learning in particular. It is positively acknowledged that the revised policy enables greater access for students with disabilities in higher education at the institution in question. However, in the effort towards transformation and inclusion, full participation by students with disabilities in the making of the institutional disability policies is imperative because that is where their voices will be heard.

References

- Chataika, T. (2007). *Inclusion of disabled students in higher education in Zimbabwe: From idealism to reality: A social ecosystem perspective*. Unpublished PhD Thesis, The School of Education: University of Sheffield, Sheffield.
- Cobigo, V. & Stuart, H. (2010). Social inclusion and mental health: Current opinion. *Psychiatry*, 23, 454.

- Creswell, J. (2008). *Educational research: Planning, conducting and evaluating quantitative and qualitative research*. Upper Saddle River: NJ, Prentice Hall.
- De Sousa Santos, B. (2008). Human rights as an emancipatory script? Cultural and political conditions. In De Sousa Santos (Ed.), *Another knowledge is possible: Beyond northern epistemologies*. London: Verso.
- Department of Higher Education and Training. (2018). Strategic Policy Framework on Disability for the Post-School Education and Training System. Pretoria: Department of Education.
- Department of Education (DoE) (2001). *Education White Paper 6: Special needs education: Building an inclusive education and training system*. Pretoria: Department of Education.
- Disability Rights Unit (2020). Wits Disability Rights Unit Annual Report 2020. Available Online: <https://www.wits.ac.za/media/wits-university/students/disabilityunit/documents/Wits%20Disability%20Rights%20Unit%20Annual%20Report%202020.pdf> Accessed: 12 March 2022.
- Farmer, P. (2005). *Pathologies of Power: Health, human rights, and the new war on the poor*, Berkeley, CA: University of California Press.
- Fotim Project Report. (2011). *Disability in higher education*. Green Paper: Foundation of Tertiary Institutions of the Northern Metropolis.
- Granlund, M. (2013). Participation—challenges in conceptualization, measurement and intervention. *Child Care Health Development*. 39, 470–473.
- Grech, S. (2011). Recolonizing debates or perpetuated coloniality? Decentering the spaces of disability, development and community in the global South, *International Journal of Inclusive Education*, 15(1), 87–100.
- Goode, J. (2007). Managing' disability: Early experiences of university students with disability. *Disability & Society*, 22(1), 35–48.
- Meekosha, H. & Soldatic, K. (2011). Human Rights and the Global South: The case of disability, *Third World Quarterly*, 32:8, 1383–1397.
- Hosking, D. L. (2008). Critical disability theory. *Disability Studies*, 2(4), 7.

- Howell, C. (2005). *Higher education monitor: South African higher education responses to students with disabilities: Equity of access and opportunity*. Western Cape, South Africa: The Council of Higher Education.
- Howell, C. (2006). Disabled students and higher education in South Africa. In: B Watermeyer, L Swartz, T Lorenzo, M Schneider & M Priestley (Eds.). *Disability and social change: A South African agenda* (pp. 164–178). Cape Town: HSRC.
- Hugo, A.J. (2012). The response of higher education institutions in Namibia to the needs of students with disabilities. *Africa Education Review*, 9(2), 308–326.
- Matshedisho, K. J. (2007). Access to higher education for disabled students in South Africa: A contradictory conjuncture of benevolence, rights and the social model of disability. *Disability and Society*, 22(7), 685–699.
- Maxwell, G., Granlund, M., & Augustine, L. (2018). Inclusion through participation: understanding participation in the international classification of functioning, disability, and health as a methodological research tool for investigating inclusion. *Frontiers in Education*, 3(41). <https://doi.org/10.3389/educ.2018.00041>
- McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., and Parkinson, K. N. (2006). Participation of disabled children: how should it be characterised and measured? *Disability and Rehabilitation*, 28, 1157–1164.
- Meekosha, H. & Shuttleworth, R. (2009). What's so critical about Critical Disability Studies? *Australian Journal of Human Rights*, 15(1), 47–76.
- Moretti, M., Alves, I., and Maxwell, G. (2012). A systematic literature review of the situation of the international classification of functioning, disability, and health and the international classification of functioning, disability, and health—children and youth version in education: a useful tool or a flight of fancy? *American Journal of Physical Medicine & Rehabilitation*. 91:S103. DOI: 10.1097/PHM.0b013e31823d53b2
- Mutua, M. (2005). *Human rights: A political and cultural critique*. Philadelphia, PA: University of Pennsylvania Press.
- Ndlovu, S. (2017). *Obstacles and opportunities in graduating into professions: The case of a University in South Africa*. Unpublished Thesis: University of the Witwatersrand: Johannesburg, South Africa.

- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16, 1–13.
- Pothier, D. & Devlin, R. (2006). *Critical disability theory: Essays in philosophy, politics and law*. Vancouver-Toronto: UBC Press.
- Republic of South Africa (1996). *Constitution of South Africa*. Available at: <http://www.info.gov.za/documents.constitution/1996> [Accessed on 17 August 2022].
- Saldana, J. (2014). Coding and analysis strategies. In P. Leavy, *The Oxford handbook of qualitative research* (pp. 581–605). New York: Oxford University Press.
- Shildrick, M. (2012). Critical disability studies: Rethinking the conventions for the age of postmodernity. In N. Watson, A, Roulstone & C, Thomas (Eds), *Routledge Handbook of Disability Studies*. Routledge.
- Titchkosky, T. (2003). *Disability, self and society*. Toronto: University of Toronto Press.
- World Health Organization (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.
- Young, I. M. (1990). *Justice and the politics of differences*. Princeton: Princeton University Press.