

Ability in disability enacted in the National Parliament of South Africa

Camilla Hansen*

Department of Community Medicine, Section of Medical Anthropology and Medical History, Institute of Health and Society, University of Oslo, 1130 Blindern, 0318 Oslo, Oslo, Norway

(Received 21 March 2013; accepted 21 October 2013)

This anthropological study describes how disabled activist and politicians transcend race segregation, exclusions, discrimination and make disability and ability in disability real in the eyes of the nation. Based upon interviews with 15 parliamentarians with disability (MP) and participations observation in the National Parliament, between 2005 and 2006, this article disentangle inclusion/ exclusion in a particular historical context and situate the role disabled politicians in building a new South Africa. In post-apartheid, exclusion is linked to ‘disadvantage communities’. These new political positions created can be traced back to the introduction of ubuntu as connected with disability and ability in new nation, as well as the association between physical disability and the structural disabilities associated with the apartheid regime. Such political narrative strategies served to create a new broad relational understanding of disability, bringing new political capital to people with disabilities and interconnect disability in the new nationhood.

Keywords: post-apartheid South Africa; diversity; reconciliation; human rights; disability politics/classification; reasonable accommodation; ability/disability; social life; inequalities

Introduction

This article investigates how South Africa’s politicians with disabilities enact their conditions in ways that express ability in disability. In the post-apartheid context, acceptance of national diversity shapes how ability in disability is enacted. These members of parliament emphasize that they represent disabled people in general. At the same time, their position in the National Parliament is legitimized by their own individual disabilities. In their powerful capacity to perform day-to-day political work and activities at a national level, these politicians transcend the common understanding that disability correlates with disadvantage (WHO 2011), and has to do with limitations in carrying out normal day-to-day activities (Equality Act, British Government 2010). This transcending of ability in disability underlines the argument that disability as a category should be investigated as culturally produced and performed within socio-political structures (Ingstad and Whyte 1995, 2007; Kohrman 2005).

In the new nation-state of South Africa, a new political human rights space has been created by disabled activists and politicians; activists interconnected in the resistance movement under apartheid. Disability politics became linked to the term ‘disadvantaged communities’, where black people, women and people with disabilities are affected by

*Email: camilla.hansen@medisin.uio.no

discriminatory structures and norms. This political space implied a unique situation, where these MPs, through their participation and mobility, were able to renegotiate and reconceptualize disability into ability and hence take an active part in the process of breaking the boundaries of the new South African society. In their activities, these MPs represented a new social practice and an understanding of disability interconnected in relationships which transcend cultural boundaries of race, segregation, separation and discrimination. This situation is brought about by the particular conditions of apartheid history and the South African process of reconciliation. The historical condition of social exclusion refers to a condition within disadvantaged communities. According to Didier Fassin (2008), these historical conditions exist as a corporeal presence of memory; as social structures and norms inscribed and imposed upon men and women, both in their everyday existence and in the meaning they give to their lives and actions (Fassin 2007, 316). According to Fassin, embodied experience of the past shapes collective relationships between disabled and able-bodied people in the present.

Disability studies were developed by disabled researchers and are connected to the disability movement in the USA and Great Britain in the 1970s (Barton and Oliver 1997; Oliver and Barnes 1998). The dichotomy of inclusion/exclusion was at the core of this movement. Disabled people reformulated their experience as being 'excluded from society', as opposed to being 'maladjusted to society'. They saw their disability as resulting from architectural, socio-economic and cultural barriers (Winance 2010, 93). This awareness is the basis of the 'social model of disability'. Along similar lines, this article demonstrates that exclusion in South Africa refers to communities with a historically disadvantaged position. Here, however, it was not only the disabled who were excluded from society; also for women, in addition to racial and socio-economic inequalities, conditions of exclusion were created that worked in similar ways.

In this article, I use the biographies of three members with disabilities in the National Parliament (during the period 1999–2009) to illustrate how exactly ability in disability become enacted.¹ These ethnographic cases illustrate how these MPs create a new embodied politics of disability. Indeed, in their political lives, these MPs embody and perform disability on an everyday basis, illustrating the inherent difficulties in being less able-bodied. At the same time, as the MPs' ability to engage depends upon the able bodies of others, these members define disability as a relational concept, in addition to establishing and embodying politics that are interconnected with broader political processes. Their actions illustrate that disability is a relationship between the individual and an assemblage of persons, objects, things and environmental structures. In this process of construction, these politicians take a leading role, and hence also create space for other disabled people to follow in their footsteps.² The underlying legal platform enables leaders and MPs with disabilities to corporeally enact values or norms, to make demands upon the wider society to pursue the implementation of these new laws, encouraging a transformation of South African society.

Ingstad and Whyte, and Korhman show us the importance of studying disability in the South with a focus on how nation-states frame disability. The South in this context offers insights into the consequences of disability in societies where institutional infrastructures are limited, and where disability as a concept and an identity may not be an explicit cultural category (Ingstad and Whyte 1995, 10; Korhman 2005). Within the post-apartheid nation-state of South Africa, disability has become explicitly co-produced as part of the process of establishing new nationhood. Through a discussion of the political work and the daily existence of disabled MPs in the South African Parliament, this article will provide an insight into these processes, and how disability becomes culturally understood.

In an effort to dismantle discriminating structures, this article reveals intimate connections between the embodied disability and the political work of MPs. Here, contemporary disability rests upon a contrast with past apartheid constructions. The insights, needs and skills articulated by disabled MPs contribute new knowledge and create new collectivities. I will discuss the ability in disability manifested by these MPs and how they partake in the construction of the new South Africa.

The new nationhood: conceptualizing disability within the framework of a rights-based approach

In the early transitional phase, Disabled People South Africa (DPSA) worked closely with the African National Congress (ANC) to develop the new Constitution. DPSA and the ANC were closely linked because a number of ANC members had disabilities or had become disabled in the course of the struggle for liberation. They shared the same fundamental understanding of discrimination and disadvantage, and the desire to make all kinds of social and physical mobility equal for all, including access to basic needs, health, education, knowledge and political influence. The process of introducing these laws for *all* citizens of South Africa laid the groundwork for a more inclusive post-apartheid society (White Paper on an Integrated National Disability Strategy 1997).

The White Paper on an Integrated National Disability Strategy (1997) interconnects these conditions of disadvantage and documents an understanding of how the apartheid system medicalized and institutionalized people with disabilities. In particular, the separation of such people from their families and communities created situations where those with disabilities were not able to make decisions regarding their own bodies and lives. In South Africa, these past structures and norms are linked to the medical model. This model defines disability as being a result of an individual, pathological or functional causality and focuses on action towards the person to be rehabilitated. The new policy re-directs the medical model with a strong critique linked to practices of institutionalization and medicalization. The new embodied disability policy links the social model with an emphasis on structural initiatives and norms that enhance participation for all, with a strong focus on employment and education.

The Employment Equity Act (1998), Promotion of Equity and Prevention of Unfair Discrimination Act (2000, 2003) and the Broad-Based Black Economic Empowerment Act (2003) targeted vulnerable groups such as black people, women and people with disabilities. The new law requires that 2% of all employees must have a disability. These new labour laws defined disability broadly, emphasizing the connection between physical and structural disability. The National Parliament fulfilled these rights and legal obligations by creating a place where politicians with disabilities could actively shape the new nationhood. In the following, we will see how the MPs with personal disabilities enacted the historical structures that caused immobility.

Post-apartheid: reconciliation and disability reconstructed

The historical condition of segregation and separation restricted, among other things, physical and social mobility, as a consequence of how people and bodies were classified. The Land Act of 1913 established independent ethnic homelands/Bantustans to facilitate 'separate development' and native reserves, and further restricted black people from moving between places (Bundy 1979). There were checkpoint controls and the police continually asked for passports, criminalizing those without papers. Passport/ID

documents (*Dom passes*) became central for mobility. The apartheid government only issued passports/ID documents to those people who were able to enrol in the labour regulation programmes. The apartheid state distributed labour between farms and towns, and only those who became migrant labourers could travel (Legassick 1977; Bundy 1977). Bantustan territories served as migrant labour reserves for the South African economy. ‘Labour reserves’ separated the household members living in ‘homelands’ from the migrant workers who lived on white South African land located in cities far from homelands or ‘native reserves’ (Comaroff and Comaroff 1987; Ferguson 2006). Sick people, or those with disabilities, were not able to obtain ID documents and were forced to remain in the homelands. Their social and physical mobility was restricted as a consequence. The inability to move (due to the lack of ID documents) restricted people’s access to health care and social services, as these were only located in urban (white) areas. On the reserves, the health care provided was limited (Giliomee 2003; Mbembe 2008, 12–14). These historical conditions are being transcended though these new laws. This spatial segregation was furthered by the creation of ‘townships’ and ‘homelands’, and allowed national government to ignore people in these areas. Bantustans were omitted from the statistics, and thus the dramatic differences in mortality rates and health care remained hidden from both national and international audiences (Fassin 2009, 55). The institution of a social, and later a legal system of racial separation did not only have affect the practicalities of life (limitations as to where to reside, how to move, have sex and marry), it also had profound consequences for biological life (nutritional status, risk of becoming ill, rates of infant death, disability, etc.) (Fassin 2009, 56). At the end of the apartheid regime, these structural conditions remained, both as lasting inequalities and as an expression of the frustration over what are seen as remnants of apartheid. The term ‘post-apartheid’ designates these frustrations (Fassin 2008, 318).

The post-apartheid reconciliation period emphasized humanity and inclusion, in contrast to the brutality of the apartheid state. In this political period, *ubuntu* was used as an ideological concept. It first appeared in the Constitution of the Republic of South Africa, Act 200 of 1993: ‘[...] the basis that there is a need for understanding but not for vengeance, a need for reparation but not for retaliation, a need for *ubuntu* but not for victimization’ (Constitution and Acts South Africa Government 2013; Epilogue after Section 251). The Constitution formed the legal background for the later Truth and Reconciliation Commission (TRC). Richard Wilson argues that *ubuntu* as an ideological concept conjoins human rights, restorative justice, reconciliation and nation-building within the populist language of pan-Africanism (Wilson 2001, 13). *Ubuntu* is a vernacular Nguni word – a version of it exists in all the major indigenous languages of South Africa – that denotes ‘humanness’, and explicitly connects personhood with intersubjectivity, with the proverb ‘a person is a person through other persons’ (in Zulu: ‘umuntu ngumuntu ngabantu’ and in Xhosa ‘umntu ngumuntungabatu’) (Tutu 2006). Antjie Krog takes Wilson’s understanding further, by stating how this local world view, *ubuntu*, was brought to the national stage, providing coherence and thereby enabling the TRC to do its work without incidences of revenge (Krog 2008, 353). The TRC commission connected *ubuntu* with concepts of forgiveness, reconciliation, amnesty and justice. To Krog, Desmond Tutu articulates the meaning of *ubuntu* by referring specifically to strangers. Desmond Tutu describes *ubuntu* as:

A person with Ubuntu is welcoming, hospitable, warm and generous, willing to share. Such people are open and available to others, willing to be vulnerable, affirming of others, do not feel threatened that others are able and good, for they have a proper self-assurance that comes

from knowing that they belong in a greater whole. They know that they are diminished when others are humiliated, diminished when others are oppressed, diminished when others are treated as if they were less than who they are. The quality of Ubuntu gives people resilience, enabling them to survive and emerge still human despite all efforts to dehumanize them. (Tutu 2006)

Nelson Mandela (2006) explains the spirit of *ubuntu* as explicitly relational: *ubuntu* does not mean that people should not enrich themselves. The question therefore is: ‘Are you going to do this in order to enable the community around you to improve?’ This refers to a way of acting within communities, sharing information, gathering people in order to help and assist and to a morality in what people *do* and how people *act*.

For 2 years, the TRC held public hearings all over the country, and investigated gross violations of human rights committed between 1960 and 1994. Over 20,000 statements by victims were recorded. This national enterprise of political confessions orchestrated by Archbishop Desmond Tutu led to a new construction of the truth about the past, based upon these testimonies. However, to many in the black majority, the past is still alive in the present, as the shame of poverty, suffering and human degradation (Fassin 2008, 317–318). According to Hansen and Sait, this also appeared in people’s own understanding of disability where the environment, lack of care, employment and basic treatment and medicine appear as part of disability. ‘You are disabled when you can’t do what you want’. ‘We can’t find work and we can’t work as we are disabled’. ‘People are dying here because they can’t travel to the doctor, we want to seek medical help and there is no doctor here’. ‘People are ill and dying, transport costs money and medications cost money, the distance is far’. ‘People here experience pain, fits, illnesses and a body which cannot do what they want’. These expressions of disability emerge as expectations towards the new democratic government to address these basic rights (Hansen and Sait 2011, 100–101).

According to Jean and John Comaroff, *ubuntu* refers to communalist, socially oriented sensibility, an ethos which permeates the constitution of the post-colony and its public discourse (Comaroff and Comaroff 2009, 44). The concept of *ubuntu* refers to a socially oriented sensibility where symmetrical relationships of support and assistance are being initiated as responsibility and reciprocity; norms for how you act or practices of ‘being’ within communities. *Ubuntu* situates the person in collectives that enhance experiences of the past.

In this open political space, embodied knowledge of disability becomes useful knowledge as a derivation of the experience of the past. The political space and opportunity enable activists and politicians to draw on their existing interdependent relationships, such as kin, or friends at work. These people become able to choose and control their work and workplace. In practice, relationships of assistance or support – symmetrical relationships – become publicly visible. As an essential cultural practice of *ubuntu*, intersubjectivity relationships are being performed. *Ubuntu* enables the person to be present, effective and perform in their work. This material draws attention to how the National Parliament becomes an arena where *ubuntu* becomes enacted, relationships included and a new embodied politics make up a new understanding of disability: ability in disability.

The National Parliament as a reflexive place

The National Parliament serves as an anthropological case where both ability and disability are enacted (1999–2009). As an outcome of their political work, DPSA and the ANC made an agreement to have leaders who were people with disabilities on the ANC

proportional list for the National Assembly. Maria Rantho became the first female MP with disabilities in February 1995. Six other leaders were included in 1999. During the period 1999–2009, the National Assembly consisted of 350–400 members, within the National Parliament. Among these were 14 members with disabilities (six of whom were ANC members) (DPSA 2001, 113–114).

Through biographies of three MPs with disabilities, Mr Mavo, Mr Njabulo and Mrs Dressen, their workplace, the National Parliament, is investigated with a view to how ability in disability was performed. These three MPs were between the ages of 40 and 50 and all currently represented DPSA. One played an important part in the apartheid struggle; another, as a leader of DPSA, was closely involved in the resistance movement; the last attended university while in exile in the USA. They not only have different backgrounds, but different disabilities: except for his arms and some fingers, Mr Mavo is paralysed from his neck down to his toes; Mr Njabulo is blind and Mrs Dressen is Deaf. Active negotiations and supporting each other as a group had enabled these MPs to create a workplace that accommodated their specific disabilities. This reasonable accommodation (UN Convention on the Rights of Persons with Disabilities 2006) relied upon the parliament to take into account the personal experiences of its members, accommodating experiences of both ability and disability.

I visited two members, Mr Njabulo and Mr Moeletsi, in the parliament in 2000. At that time, the parliament building had been made accessible – easy to move around with a wheelchair, loudspeakers for calling members into the Assembly, and lifts with announcements. At the same time, all three were frustrated that they had no assistive devices to help with reading information, and that their offices were spread all over. Mr Njabulo was placed in a corner where he felt marginalized. By 2004, when I met them again, they had managed to negotiate office space on the same floor and were given assistive devices, secretaries, cars and accommodation. I witnessed the tremendous impact these improvements had on the way these MPs interacted with others, on their ability to move around, to take the initiative, and express themselves in the National Assembly, as well as on different commissions, and to engage in making policy and laws.

For these MPs, the parliament became a place for members ‘to build themselves up’ by making alliances and to accumulate agency and personhood required in their capacity as politicians. Not only did the members become role models for other leaders of disabled people’s organizations, but the establishment of MPs with disabilities as an elite group also contributed to the institutionalization of assistance systems that could also benefit other disabled people, in state departments, organizations and institutions, as well as more broadly in private enterprises. Furthermore, the environment they created made an impact on how people with disabilities understood themselves, and it was talked about as an example of performing ability in disability.

Transcending embodied disability politics

Njabulo entered parliament as a chair of DPSA. He had long provided strong leadership within the disability movement, representing the largest and most powerful disability organizations. He spoke fluent English and talked about the movement with great rhetorical skill; he talked about the achievement of the new laws, language and policy as the success of the movement:

Disabled people now have a framework they can use. It is our work, he says, and he is proud of that. There is so much that needs to be done in the local communities to make people

understand and be able to use these policies. Since 1999 we have succeeded here in parliament, but we have not succeeded in government departments or locally. People who live in remote areas do not see the consequences of the new Disability Acts. As part of our policy work we emphasize that it is important that we as persons with disabilities do this work ourselves. The slogan “Nothing about us without us” is about that. Here in parliament it is very hectic, and there is a lot to do. We have worked hard in order to be represented in all the relevant committees. Disability is about transportation, accessible buildings, schools, education and employment as well as other aspects of society important to make our voices heard. We as persons with disabilities are involved in processes of building a new South Africa for all. In this process we show that we as disabled also can function. We must become visible, showing that we are able even though we are disabled. We even have to be involved as business people.

Njabulo makes a strong statement for how the embodied disability politics become a responsibility for people with disabilities. Disabled people need to reach out to communities and include more disabled people, as he states the political aim to make disabled people visible to the public through the slogan ‘Nothing about us without us’.³ He addresses the layers that disabled people must create in their own lives, using disability politics as a way into socio-economic sustainability. This community focus is strongly emphasized in his statement, but also in how he addresses people individually.

As noted above, Njabulo is blind. He moves around with one other person he holds on to. In common with all the MPs, his work schedule was full. Being present in parliamentary group meetings and presentations, disability politics was part of his daily work. In addition, he worked as the national Chair of DPSA. In his workplace at the National Parliament, he was allocated a secretary in addition to a driver. Njabulo received help with translating documents into Braille and he had been given a special machine for that purpose. The secretary also helped him to book appointments, receive and circulate information. During our interview, he commented upon how the parliament had been very supportive in accommodating his family situation. He was a single father and all his children lived with him. His children are very important in order for him to make progress in his work: ‘I could not be here without family and my children: they are my eyes’. Njabulo thought that parliament had incorporated an understanding of disability, not as an individual issue, but rather by seeing disability as the need for significant relationships, and, more importantly, that it had allowed members to make room for these relationships. Njabulo explains further:

I never use a cane or a dog, but I acknowledge that people can make use of these technologies. I use those people I have around me as my eyes. I live with them; it is part of my Zulu culture; I grew up like that. There were no canes or dogs, but people.

This has given him a platform from which he could learn to communicate with the public, and be active in the struggle against apartheid. Njabulo trusts people around him, constantly using the eyes of others; his interdependency becomes visible in the eyes of others. In the way he moves and talks, he is interconnected in a relational space. He expects people to tell him when there are steps, and how he can move around, and he feels how the other person moves and he moves with them. His social awareness, memory and strong ability to orient himself in the environment and also in his political engagement interconnect him within these collectives. Njabulo works very closely with the other MPs and they often help each other out by supporting and assisting each other day to day, in order to perform more effectively. As a group of disabled politicians, they were confronted with norms of effectiveness that they continually needed to contest. As

MPs, this was always present in their minds, and they had to work doubly hard in order to gain acknowledgement from others. He emphasized how a special relational understanding among the MPs with disabilities created a much stronger initiative for disability enactment among the public. As an interconnected group, they became stronger by reaching out to a sphere which used to be closed to them. Looking back he said: 'We have achieved so much. We have made disability visible'.

Njabulo's increased performance of individual ability lay within a heritage of relationships and cultural understanding of *ubuntu*. His skilfulness in political leadership influenced how people with disabilities could take part in decision-making processes. At the same time, he was creating a specific disability platform, which other people with disabilities could use to develop projects and programmes and to establish themselves as entrepreneurs to create profit: knowledge of disability became a skill when a more inclusive society was in the process of being established.

Reconciliation and diversity

My difficulties in even making contact with these MPs to arrange interviews were the consequence of such a hectic working environment – being on the move. Fixed appointments changed constantly and something more important seemed to turn up every time. However, over time I managed to meet most of them several times both formally and informally. Mr Mavo was a busy MP but once I had managed to pin him down he was keen to talk to me. He was an open person and had ambitions to make disability understood through both his personal experiences and his political work. It helped me that he was highly aware of the contribution of the Norwegian state during the apartheid era:

You see I am different from the others here in parliament; I have a different background. I have been to prison, many times, during the struggle; I sat in the same prison that later Mandela was moved to. I want you to understand the difference. This makes me different. The car accident happened after I was released; it was a difficult time that day. We were chased by white Afrikaner farmers because we had distributed forbidden information, and in this situation at high speed I lost control of the car and I was thrown out of the front window; the others in the car were not injured. I became paralysed from my neck down to my toes – luckily I can move my arms and some of the fingers. I have always been on the move and after the accident I just continued what I have always done – moving back and forth – meeting and connecting other people together. I used to be a journalist.

Like Mr Njabulo, Mr Mavo expressed the importance of his family, daughters, brothers, mother and friends in the community where he was born. He had received much help after the car accident. He emphasized his relatedness to the community, being part of and representing their demands, talking, mediating disputes, explaining issues that people did not understand.

Mr Mavo could move his hands freely; he totally depended upon his electric wheelchair, but he could drive it himself. His cell phone was his main means of communication. He constantly kept in touch with people. He made his own schedule and he was continually on the move from early morning until late evening. He said to me that to be present all the time was his focus. His strength, he said, was clear communication. He spoke Xhosa and Afrikaans, which often gave him the role of intermediary. These skills had helped him to maintain his position within the ANC. Mr Mavo constantly had to make arrangements so that he could move around. This required assistance. Day and

night, he was always accompanied by at least one person. To be able to move, he needed two people to lift him in and out of the car. He needed assistance to change position in his wheelchair.

After meeting Mr Mavo several times, I also got the opportunity to follow him around in his work. This made it possible to have more informal conversations as well as to observe how he communicated and interacted with others, and see what assistance he received throughout everyday situations. By spending time with him, I obtained a deeper understanding of how he used the people around him to build relationships within the community. In these situations, he made himself available through his distinctive way of communicating with others, his ability to take part in others' lives and to let people be part of his.

Mr Mavo had a seat on the transport commission; in addition, he worked as a mediator and was called upon in different conflict situations to devise solutions. Racial tension, conflict over housing, plus working conditions at schools, institutions and companies are among the issues he has had to deal with around the Western Cape area. He talked about how people should use their rights. These skills require the power of words; he has spoken many times in the National Assembly, and presented cases in the media. Being on the move, meeting people, having conversations, sometimes in his wheelchair, sometimes in his car, talking with people through the window, these situations demanded his full participation. He got involved in other situations, other people's concerns, concerns that became embodied as part of him, and he participated actively, experiencing the desires, frustrations, hopes and feelings that made up these encounters. He described this as painful because it was difficult to share in people's suffering. His focus on mobility created structures that needed to be in place so that he could meet and interact, and thus he effected broader change through his presence and his mobility issues.

I see the way Mr Mavo acted, moved and built relations through others as part of social exchanges. His way of 'being in the world' reflected common shared values in South African society. As Comaroff has pointed out, here self-construction occurs in relation to others and it is a creative process of making oneself a social person (Comaroff and Comaroff 1987, 197–198). This social presence was also reflected in how Mr Mavo perceives himself as disabled:

It is only when I can't move – when I am stuck – then I really feel my disability; then I feel dependent, when there are no people I can ask for assistance and I am alone and the time goes without me. This happens regularly; those around me are also people, lots of things happen to them which have an impact on my life. I have to find a balance in what I ask people to do for me. This is not always what people do, and what they accept to do; that is not so easy – so I try to be focused, to prioritize what I need help for. Sometimes it does not happen in the ways I want; those around me are also people – things happen with them and sometimes they simply do not turn up. I do not like it but this is what my disability is about. I try to make myself easy for others, so that people can easily move me. But they get tired, do not follow up, and sometimes it is difficult to find reliable people to assist me.

Mr Mavo described his disability as a stage of losing control; his vulnerability was interconnected with other people. He was dependent upon other people to be able to move. In his statement, the paradox revealed itself: as he received help from people he knew within his community, his vulnerability became interrelated with other people's everyday challenges.

Comparing the example of Mr Mavo to that of Mr Njabulo, both acted within the same understanding of *ubuntu* by increasing individual corporeal ability through relationships and showing disability leadership. They both shared the same agenda to

reconstitute disability, as Erving Goffman famously put it, from 'leaning on his crutch' to becoming someone who 'play[s] golf with it' (1989, 10): to reconstruct and renegotiate society, thus making mobility a political issue, in the broad sense, through their own significant experience.

Sharing common ground: making disability visible

Mrs Dressen was the one among the three MPs who had received special education in the USA; she is Deaf and uses sign language. She was an advocate for sign language as an official national language. This would require more education for all, as well as a system for sign-interpreters. Her political work actively linked these specific issues to a broader disability agenda. She explained that she was creating a shared platform for constructing disability relationally within a framework of discrimination, sharing common ground with Mr Mavo's and Mr Njabulo's work:

As Deaf people in South Africa we need to consider our past history and the socio-economic inequalities such a history has produced. These historical structures have shaped people with disabilities, and discriminated against them with less access to school, higher education, and health care. In such a way Deaf rights have a common agenda with the broader disability movement here in South Africa. People are very poor, and many children are not getting good enough schooling close to where they live, so they need to move away from their families, and some cannot afford to live with their family and go to school. Many Deaf children do not learn sign language, rather finding other ways to communicate without words. In rural areas many deaf children grow up without learning sign language. To be able to communicate and express your feelings are very important. In such a way children and youths are being discriminated against continuously, since we have not managed yet to create facilities for all. In post-apartheid the Deaf Organization comes under the disability umbrella. Such positioning is highly political, and differs from how you see Deaf people organizing themselves in northern Europe or the USA, where the Deaf as a group fight for their own language, similar to indigenous peoples.

Mrs Dressen found it unproblematic to work under the disability umbrella; during apartheid, deaf organizations have a single-impairment focus. In post-apartheid, Mrs Dressen's position is linked to the new laws and policy. She connects Deafness to disadvantaged communities, and hence transcends old structures within Deaf organizations. For example, she explained:

I relate very much to the agendas of the other MPs who are disabled; we meet up, and we are a group here in the parliament. As Members of Parliament we also do work in our constituencies, and throughout the year we are in between parliament and the areas where we live. I spend a lot of time in communities talking about my life as a Deaf person and discussing what people can do. My schedule is tight; I get invited to many places, not only in my home province but throughout the country. I really like my work. People complain and want their rights, but there are too few of us to address people's needs in the field of disability rights.

Our agenda is to make disability visible. We want employees to employ more people; when you employ a person with disabilities you usually have to employ one or two more people. Disability creates work opportunities for others. We develop knowledge about our needs, but also how to improve working conditions for these assistants.

She also emphasized that as a disability group it was much easier to tackle these issues, and the group becomes stronger politically:

As we move together we interact with other MPs with disabilities. When we are together we help each other; the way it works is that Mavo's or Njabulo's personal assistants also help me if needed, or Njabulo and Mavo help each other. Being together as a group has made us stronger, more able to articulate our demands for more accommodative practices, we also enjoy our work more and we like to be a group.

Mrs Dressen refers to a form of sociality defined by being heard, being touched, being seen among people with different disabilities. This form of sociality follows from the fact that these MP know each other. These close connections are also facilitated by the National Parliament locating their offices on the same floor and also creating residences within the same compound. Mrs Dressen transcends her bodily disability by her insistence on including Deafness in another kind of discourse on disability altogether. Her demand resonated with the previously mentioned historical trajectories, where ability and mobility were restricted on the grounds of racial segregation. She was adamant that these former apartheid practices resulted in the same paralysis as the state of Deafness. This focus highlights deafness as being interconnected with the agenda of making disability visible.

Conclusion: new collectives – interdependency through relationality

This paper has shown the importance of situating disability in a methodological framework of analysing what people are doing, of examining practice as well as investigating the historical, political and socio-economic context. This framework follows people in what they do a practice which focuses upon how disability becomes interconnected. This article has disentangled inclusion/exclusion in a particular historical context, and situated the role of disabled politicians in building a new South Africa. Their ability to address historical trajectories of inequalities and to maintain an awareness of these historical conditions becomes crucial in building the future South Africa.

In post-apartheid South Africa, disability becomes understood as an assemblage between environment, persons, objects and things. The concept of disability was made part of a larger concept of disadvantage, referring to socio-economic condition of exclusions associated with race segregations. In my study, MPs working in the National Parliament made disability visible in the eyes of the new nationhood. They physically represented how history imposed structures on people in disadvantage areas.

These MPs express their ability as relational, as depending on family and technology. The way of articulate the self in relations to others exist as a moral humanness constructed as a national ethos, through the notion of *ubuntu*. As Hacking (1999) has pointed out, nation-state classifications of subjecthood here too shaped peoples experiences of themselves. This article has described how these MPs within the new nation-state create and enact disability politics by the use of their own bodies. Mr Njabulo creates collectives of disability in his strong focus upon making disabled people visible in the public (Whyte 2009). Mr Mavo has managed to act as a mediator when frustrations are articulated and expressed among people in disadvantage areas. Mrs Dressen manages to incorporate Deafness into the broader disability agenda, addressing disadvantage communities. These MPs act in their own capacity and enskillment, organizing support and assistance, draw upon knowledge from able bodies to enhance achievement in their work. Their approach to employment both disentangles the asymmetric relationships between able bodies and persons with disabilities, in their enactment disability knowledge gives position of control and status of achievements. Their own individual disabilities become reproduced as corporeal challenges to be solved

by the help of people, technologies and adjusted environments. These physical corporeal signs are rewritten by drawing the emphasis on interdependency and made aspects of the new national *ubuntu*. *Nothing about us without us* represents this shift in the new nationhood.

Acknowledgements

I would like to thank the politicians and activists in South Africa, for their time, trust, allowing me to take part in their work, and wanting to be part of this work. Gro Ween for making my English readable and maintaining a partner role. Associate Professor Emeritus Benedicte Ingstad and Professor Paul Wenzel Geissler for reading and commenting on the manuscript throughout the process. Colleagues at Section of Medical Anthropology and Medical History, Institute of Health and Society, University of Oslo for their comments. Part of this work has also been presented at the Yale University: Society for Medical Anthropology of the American Anthropological Association: Medical Anthropology at the Intersections: Celebrating 50 years of Interdisciplinary (2009). Norwegian Research Council for funding this project.

Notes

1. This anthropological study has been approved by the ethical committee at University of Cape Town, The department of Social Anthropology. The material collected from the National Parliament is based on repeated interviews with MPs in 2005–2006. They all gave consent. The finished text has been approved before the end of publishing. Original names do not appear. The author/researcher takes full responsibility for the whole text. This anthropological study run out of a broader interdisciplinary research between University of Cape Town, Department of Health Science, DPSA, University of Oslo, Institute of Health and Society, Section of Medical Anthropology and SINTEF, Oslo. The research Living Conditions among People with Disabilities in Eastern and Western Cape 2004–2005 were approved by the medical ethical committee, and were funded by the Norwegian Research Council and South Africa Research Foundation.
2. The anthropological material on which this article is based was gathered during a total of 12 months of fieldwork between 2004 and 2007 using multi-sited ethnographic methods. I was interested in the ways that these politicians made sense of their situations and the content of their political engagement. I moved between places, media, organizations, health institutions and households, between the elite and grassroots experts, and between people living in poor settings. The very heart of the design for this multi-sited ethnography was following these politician's connections, associations and relationships (Marcus 1995). The intention was to bring the various locations and contexts into the same frame of study. For this research, I conducted repeated in-depth interviews with 15 leaders and politicians, participated in hearings in the National Assembly in the National Parliament, attended three workshops, three conferences and 20 local as well as national public gatherings, *imbizo*, where disability awareness is publicly celebrated (including National/International Day of Persons with Disabilities). I also followed politicians with disabilities throughout their everyday life, at work and at home. The working language was English, and I used the same people I was interacting with as interpreters if this was needed. Many of these people I have known since 1999–2001, revisiting after the first fieldworks in South Africa in 1995–1996.
3. The slogan 'Nothing about us without us' has been taken up by the South African disability movement. 'Nothing about us without us' was first used by David Werner (1998) in describing the development of innovative technologies in developing countries. The term has since been used as a slogan within the Disability Rights Movement, especially in the USA, and it is also strongly visible in South Africa. It is about power to the people and the demand for control; the quite militant and revolutionary message is that politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. Since people with disabilities have needs, this creates dependency and furthers the dependency when people are born into powerlessness, poverty, degradation and institutionalization. 'Nothing about us without us' points towards these power relationships with active representations (Charlton 1998).

References

- Barton, Len, and Oliver Mike. 1997. *Disability Studies: Past, Present and Future*. Leeds: Disability Press.
- Bundy, Colin. 1977. "The Transkei Peasantry." In *The Roots of Rural Poverty in Central and Southern Africa*, edited by Robin H Palmer and Neil Parson, 201–220. London: Heineman.
- Bundy, Colin. 1979. *The Rise and Fall of South African Peasantry*. Los Angeles, CA: University of California Press.
- Charlton, James. 1998. *Nothing About Us Without Us: Disability, Oppression and Empowerment*. Los Angeles, CA: University of California Press. doi:10.1525/california/9780520207950.001.0001.
- Comaroff, Jean, and John Comaroff. 1987. "The Madman and the Migrant: Work and Labor in the Historical Consciousness of a South African People." *American Ethnologist* 14 (2): 191–209.
- Comaroff, John, and Jean Comaroff. 2009. *Ethnicity, Inc.* Chicago, IL: The University of Chicago Press. doi:10.7208/chicago/9780226114736.001.0001.
- Constitution and Acts South Africa Government. 2013. Accessed March 20. <http://www.info.gov.za/documents/constitution/index.htm>.
- Disabled People South Africa. 2001. *DPSA: An Empowerment Tool Pocket Guide on Disability Equity*. Cape Town, South Africa: DPSA Parliamentary Office.
- Equality Act, British Government. 2010. "Definition of Disability." *British Government*. Accessed March 20, 2013. http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068
- Fassin, Didier. 2007. *When Bodies Remember*. Los Angeles: University of California Press. doi:10.1525/california/9780520244672.001.0001.
- Fassin, Didier. 2008. "The Embodied Past. From Paranoid Style to Politics of Memory in South Africa." *Social Anthropology* 16 (3): 312–328. European Association of Social Anthropologists. doi:10.1111/j.1469-8676.2008.00045.x.
- Fassin, Didier. 2009. "Another Politics of Life is Possible." *Theory, Culture & Society* 26 (5): 44–60. doi:10.1177/0263276409106349.
- Ferguson, James. 2006. *Global Shadows: Africa in the Neoliberal World Order*. Durham, NC: Duke University Press.
- Giliomee, Hermann. 2003. *The Afrikaners: Biography of a People*. Cape Town: Tafelberg.
- Goffman, Erving. 1989. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Hacking, Ian. 1999. *The Social Construction of What?* Cambridge, MA: Harvard University Press.
- Hansen, Camilla, and Washeila Sait. 2011. "'We Too are Disabled': Disability Grants and Poverty Politics in Rural South Africa." In *Disability and Poverty: A Global Challenge*, edited by Arne Eide and Benedicte Ingstad, 93–119. Bristol: The Policy Press.
- Ingstad, Benedicte, and Susan Reynolds Whyte. 1995. *Disability and Culture*. Los Angeles, CA: University of California Press.
- Ingstad, Benedicte, and Susan Reynolds Whyte. 2007. *Disability in Local and Global Worlds*. Los Angeles, CA: University of California Press.
- Kohrman, Matthew. 2005. *Bodies of Difference*. Los Angeles, CA: University of California Press.
- Krogh, Antje. 2008. "'This Thing Called Reconciliation...': Forgiveness as Part of an Interconnected –Towards-Wholeness." *South African Journal of Philosophy* 27 (4): 353–366.
- Legassick, Martin. 1977. "Gold, Agriculture, and Secondary Industry in South Africa, 1885–1970: From Periphery to Sub-Metropole as a Forced Labour System." In *The Roots of Rural Poverty in Central and Southern Africa*, edited by Robin H. Palmer and Neil Parsons, 175–200. London: Heineman.
- Mandela, Nelson. 2006. *Web Video of Nelson Mandela Explaining the Concept of Ubuntu*. Accessed March 20, 2013. <http://youtube.com/watch?v=Dx0qGJcm-qU>.
- Marcus, George E. 1995. "Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography." *Annual Review of Anthropology* 24: 95–117. doi:10.1146/annurev.an.24.100195.000523.
- Mbembe, Achille. 2008. "Passage to Freedom: The Politics of Racial Reconciliation in South Africa." *Public Culture* 20 (1): 5–18. doi:10.1215/08992363-2007-012.
- Oliver, Mike, and Collin Barnes. 1998. *Disabled People and Social Policy: From Exclusion to Inclusion*. London: Addison Wesley Longman.

- Tutu, Desmond. 2006. *Ubuntu – African Philosophy*. Accessed March 20, 2013. <http://www.buzzle.com/editorials/7-22-2006-103206.asp>.
- UN Convention on the Rights of Persons with Disabilities. 2006. *United Nations*. Accessed March 20, 2013. <http://www.un.org/disabilities/default.asp?id=150>.
- Werner, David. 1998. *Nothing About Us Without Us. Developing Innovative Technologies for, by and with Disabled Persons*. Palo Alto, CA: USA HealthWrights.
- White Paper on an Integrated National Disability Strategy. 1997. Office of the Deputy President, T.M. Mbeki. South Africa.
- WHO. 2011. *World Report on Disability*. Geneva: World Health Organization.
- Whyte, Susan Reynolds. 2009. "Health Identities and Subjectivities: The Ethnographic Challenge." *Medical Anthropology Quarterly* 23 (1): 6–15. doi:10.1111/j.1548-1387.2009.01034.x.
- Wilson, Richard A. 2001. *The Politics of Truth and Reconciliation in South Africa – Legitimizing the Post-Apartheid State*. Cambridge: Cambridge University Press. doi:10.1017/CBO9780511522291.
- Winance, Myriam. 2010. "Care and Disability Practices of Experimenting, Thinking with and Arranging People and Technical Aids." In *Care in Practice: on Tinkering in Clinics, Homes and Farms*, edited by Anne Marie Moi, Ingunn Moser, and Jeanette Pols, 93–117. Bielefeld: Trascript Verlag.