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Trembling narratives: In between medical classifications and indigenous knowledge explanations

The narratives presented in this article were collected during two periods of fieldwork in post-apartheid South Africa. The narrators were people I have known for some time. They experience problems with convulsions, spasticity and tremors and have sought various forms of protection, healing and treatment. To me, their stories have sparked an interest in the way that diseases and health problems are being classified and understood, and how the various interpretations influence people's perception of afflictions and the afflicted, which in turn has an impact on the social standing of the people concerned and their relationships with other people. My work is based on a sociocultural understanding of afflictions and the afflicted. In my view, such perceptions are rooted in historic, political and social processes that are reflected in individuals and their bodies. In this context, the body becomes an existential foundation for culture and subjectivity (Csordas, 1994), and afflictions such as convulsions and spasticity are not reduced to mere physiological and biological processes. Based on how local practices encompass healing and indigenous knowledge system create an alternative to explanation within biomedical knowledge system. I discuss social constructs that shape perceptions of person and self, and which are also key to how people with specific health problems may appear in society.

According to Ian Hacking (1999), historically rooted social constructs emerge as products as well as processes. Hacking concerns himself with processes that continuously shape the classification of diseases and afflictions, that shape health-related concepts such as 'disability', as well as medical practices. He maintains that the medicalisation of diseases involves not only a form of biological reductionism, but also a fusion of political, moral and existential phenomena. These are phenomena that shape the perception of what a person is and how a person presents in society. A fusion of different phenomena means that medicalisation will play out differently from place to place, and that it arises through a process. According to Kohrman (2005), a medicalisation process contributes to the individuation of the affliction and the self and establishes group distinctiveness by differentiating between the people concerned. Kohrman maintains that this differentiation

takes place on a continuum that extends from ‘the healthy’, ‘the high-functioning’ and ‘the stable’ at one end to ‘the sickly’, ‘the unsound’ and ‘the dangerous’ at the other end. Medicalisation involves the mapping of what constitutes the ‘deviant’, ‘contagious’, ‘special’ or ‘different’ individual (Kohrman, 2005).

In post-apartheid South Africa such medicalisation processes arise on both local and national levels. The various causal explanations and classifications of ‘convulsive states’ that are discussed here, such as the presence of spirits (indigenous knowledge), learning difficulties, disability and epilepsy (biomedicine), shed light on how the medicalisation process is fashioned nationally and locally, and specifically how knowledge about protection and healing shapes the perception of individual people in relation to others. By presenting three different narratives, I reflect on how causal explanations and classifications combine to structure the perception of afflictions and the afflicted, and how this in turn impacts on people’s everyday lives and social standing.

The first narrative: convulsions and tremors as a sign of learning ability and indigenous knowledge.

During my first period of field work in the northern province of South Africa I learnt about Kate, a girl in her teens. Her mother was an acquaintance of the family I stayed with, and she contacted me at a time when her daughter felt unable to attend school. She struggled with various afflictions such as fatigue, apathy, sleeplessness and convulsions throughout her body. She was sent home from school, and her mother was very worried about her health and her education. When we met, it was clear that the mother was seeking help to see a doctor, and I offered to accompany her. During the appointment, the doctor examined Kate, but he raised few queries. He took no samples for testing and saw no reason to refer Kate to any kind of specialist. The doctor, who was a fluent English speaker, turned to me and explained that he believed this was a case of learning difficulties. He asked me to explain the situation to the mother. When I responded that it would be preferable for him to address her directly, he hesitated and was unwilling to spend much time on doing so. I discussed this with Kate’s mother afterwards. She showed little interest in the doctor and his assessments and said that this was all as expected. It would appear that she had seen the doctor with the intention of acquiring a form of insurance cover; in order to be able to answer those who might ask if she had taken the teacher’s advice, including seeing a doctor. She had sought my assistance with a consultation she knew would be difficult.

After I had visited Kate's mother numerous times, she told me about Kate's night-time dreams and that Kate was being visited by ancestral spirits. The mother was familiar with such things and took the signs seriously. She needed no assistance in this area. She went to see a healer and instigated the necessary rituals. I was invited along, but she had no need of my practical assistance.

Kate's story demonstrates the complexity of people's lives as lived. Kate's fatigue, sleeplessness and convulsions were referred to as her being 'loose'. She consulted healers who saw her spasticity as a symptom of a specific condition, 'spirits in the stomach', where spirits had taken residence inside her (Hansen, 2001). A 'loose' body can only be cured through the afflicted person's relations, whether human or non-human. The mother therefore organised a ritual for the ancestral spirits (*malopo*), which was attended by Kate, her relatives and people from the local community. The ritual served to establish contact with non-human as well as human relations, with the hope of Kate becoming 'firmer'. The relationship between the non-human and the human was manifested in the ancestral spirits having taken residence in Kate's body and the ritual was a conduit for a message to be interpreted by the healer. Based on the healer's interpretation of the spirits' message, Kate's mother commenced and organised activities that mobilised relatives, friends, neighbours, experts and various material objects. These activities and objects were intended to bring Kate closer to her ancestral spirits, but also to her mother and other people within the local community.

The *malopo* ritual generated a new narrative about the cause of the convulsions and spasticity, and the explanation put Kate in a new interpretive context. While her convulsive state and tremors were caused by the spirits that had taken residence in her body and were working within her, she had also been instilled with a capacity: Kate's convulsions were signs that she was gifted with special talents. One ancestral spirit who had taken residence in Kate's body, was her maternal grandmother's deceased brother, who had been a healer. This was interpreted as a sign that Kate was *chosen*, that she had powers of healing which she would be able to develop and gain recognition from. She could become a healer and thereby help other people. The fact that this spirit had taken residence in her, was considered to be a gift, and by reciprocating, the relation could be maintained and developed over time. This relation would enable Kate to receive the spirit's strength and healing powers. In contrast to the diagnosis received in the doctor's surgery, where Kate's convulsions and tremors were seen as symptoms of 'learning difficulties', Kate's 'loose' body was considered by the healer, through the ritual for the ancestral spirits, to signify a capacity that would enable learning and the development of healing powers (Hansen, 2001).

In Kate's story we see that her affliction is addressed by local indigenous healers who were close to Kate's life, unlike the medical doctor. Kate lives in an area with an abundance of faith-healers, *ngaka ya Sesotho*, of various descriptions. Their common denominator is their ability to interpret signs from the spirits, thereby giving them an entitlement to order or instigate various forms of healing. Another common denominator is that they establish small charismatic churches where they combine ancestral beliefs with Christianity and offer healing and *community*. This type of church has a vast following throughout southern Africa. The largest of them is the Zion Christian Church (ZCC), whose holy site is in the local area. Every Easter, people from all over southern Africa go on pilgrimage to this location.

It is an interesting aspect of this story that Kate's spasticity and 'apathy', and the fact that she felt unable to keep up at school, were interpreted as a 'loose' body that had to be 'strengthened'. 'Looseness' is part of a body-and-mind construct which necessitates seeking protection to make the body 'firm' again by strengthening the body and the individual in relation to other people. By bringing the spirit of her grandmother's brother into the collective context of the ritual, the spirits who had taken residence in Kate's body let go, in the sense that the convulsions subsided.

Key to this interpretation is the differentiation between levels of severity, determined according to which part of the body the spirits have taken residence in: 'spirits in the head' versus 'spirits in the stomach'. 'Spirits in the head' involves only a brief seance during which spirits fill the body and trigger convulsions and howling, a situation during which the individual may fall to the ground and display spastic convulsions. Shortly thereafter the spirits will let go of the body and depart. Such events are commonplace during church assemblies but can also be achieved through the intake of water or through prayer, singing, dancing and communal night-time gatherings. These are events that strengthen relations with the ancestors, thereby providing protection in everyday life (Hansen, 2001). Kjersti Larsen's rich analysis from Zanzibar (2008) describes how a similar phenomenon, 'climbing to the head', demonstrates how humans and spirits are interwoven in various encounters that make up everyday life. In South Africa, spirits that take residence in the stomach were considered to be a more serious condition which required the performance of a *malopo* ritual.

Kate was left on her own for long periods of time, a fact noted by her teacher. Kate fell increasingly behind with her schoolwork, and according to the teacher, the responsibility lay with the mother. Consequently, 'protecting' Kate became a key objective, and the mother initiated activities such as the *malopo* ritual that might strengthen the mental and emotional ties between mother and daughter as well as Kate's relations with other people. Invoking the

spirits requires the presence of a healer and someone who is considered to have a close relationship with the afflicted person. There also needed to be an ‘audience’ in order to create an atmosphere that would invoke the spirits that potentially had taken residence in Kate’s stomach. The atmosphere created by those present was key to re-establishing relations with her grandmother’s brother, but also relations with the mother and those close to her. This would help to banish the spirits that had possessed Kate’s body. It was also necessary to perform the ritual relatively soon, and to repeat it in order to maintain the contact. Annual repetitions are common. The healer had pointed out that any delay would have the likely effect of prolonging the convulsive states for some time.

It is determined by socioeconomic circumstances how soon a family or a household will be able to have the necessary rituals performed that might change someone’s state of health or general situation in life (Hansen, 2001). Kate’s mother found that being short of money represented a major problem, as *malopo* is a costly ritual. The provision of refreshments makes it more likely that people in the community will in fact turn up and take part in the ritual. Kate’s mother was responsible for the catering, which involved providing a goat to be slaughtered and prepared during the ritual. Kate’s father did not attend and did not contribute financially. The first time I met them, Kate’s mother had not had a permanent job for years. She worked as a domestic help and took on incidental jobs in the nearest town, changing employers frequently. Kate had two older brothers who worked in Johannesburg, but they returned home only a few weekends a year.

The second narrative: convulsions as disability and epilepsy

During the apartheid era, there was a growing movement of disability activism which explained diseases and health problems in terms of the segregation policy. These explanations and interpretations referenced the marginalised in society and areas or settlements where difficult living conditions led to dependency and poverty. Diseases and functional impairments were considered to be the result of failing infrastructure, such as the absence of electricity, clean water, schools, medicines and social support schemes. In the late 1970s and early 1980s, self-help groups were formed for people with disabilities who lived in poor townships with little or no infrastructure. These groups were conscious of environmental barriers that impacted on people’s bodies in the form of diseases and afflictions. One of the strongest groups was the *Self Help Association of Paraplegics* in Soweto (SHAP). Friday Mavoso, a charismatic political leader in Soweto whose legs were paralysed after being shot by a policeman, became an important SHAP leader. The group highlighted that an important

cause of polio was the poor access to vaccines, a shortcoming which particularly affected the many black members of the self-help groups.

The local self-help groups (*by* organisations) spearheaded the development of an alternative understanding: self-representation, and the message and will to take control of one's own life, had been rooted in a context that traditionally had been led by professional healthcare workers (*for* organisations). The message was that people should be allowed involvement with their own treatment, thereby giving them a voice to talk about their own life and their own situation. Inspired by the *Black Consciousness Movement* and Steven Biko, they promoted the notion that society was responsible for the socioeconomic marginalisation experienced by the majority. Gradually, a larger national '*by* organisation' emerged, *Disabled People South Africa* (DPSA). In the post-apartheid era, members of the DPSA were promoted to important political offices, thereby putting them in key positions in the new government and civil service, enabling them to shape new policies and legislation in several areas, including the health and social services sector.

In parallel, other organisations emerged in the 'white' towns, headed by health service professionals. These *for* organisations were more focused on treatment in accordance with biomedical diagnoses. Many were named after specific diagnoses: *South Africa Epilepsy* is but one example. This organisation, which explained convulsions as a neurological disorder, was to exert significant influence on the understanding and classification of 'convulsive states'. The organisation's medical experts mapped the treatments available for epilepsy and argued for improved access to medication and medical technology. The objective was to disseminate information about what epilepsy *is*, and to develop a high standard of care services in the form of specific types of treatment. However, the expertise and the medical treatment services were linked to specific locations, the 'white' towns, where there were clinics with good access to medicines and specialised technology as well as diagnostic instruments such as EEG and telemetry. The organisation did not work in the poor townships or in the ethnically segregated black homelands, or *bantustans* (see below).

By comparing *for* to *by* organisations, we find that they draw on different knowledge sources. Where one focuses on a broad, all-inclusive classification of disability, the other focuses on a more reductionist biomedical approach to treatment. The classification of epilepsy as a medical specialism is promoted while problems of place and marginalisation are entirely absent. Consequently, *for* and *by* organisations are rooted in different understandings of disease and health, and they put different emphasis on the impact of the environment on people's standard of life and on their health. The *by* organisations base their notion of

disability on resistance to a dichotomous classification (Kohrman, 2005) that differentiates between ‘sickly’ and ‘healthy’, ‘able-bodied’ and ‘disabled’, ‘ability’ and ‘disability’ – categories that may serve to pathologise people’s afflictions. They seek to define disability as a result of discriminating social structures. If the causes of epilepsy are contextualised against the consequences of life under apartheid, then violence, trauma, substance use, long-term dependency and infections will appear to trigger symptoms of fatigue, tremors, spasticity and convulsions – symptoms that do not refer to the epilepsy diagnosis, but that are instead a result of the suffering that the apartheid system has imposed on the majority of the population.

Historic demarcation lines

Political systems and ideologies influence our understanding of disease and disability and how these concepts are explained. The South African segregation policies of the apartheid era created acute inequalities in the population’s standards of life, and living conditions, including their access to health services. In turn, this impacted on their explanation and interpretation of diseases and afflictions. One of the intentions of apartheid was to establish *bantustans*, geographically designated territories for each of the various bantu-speaking populations. This separation into designated areas according to ethnicity was enshrined in law through the *Land Act* of 1913 (Bundy, 1977). The law split the population. The majority were forcefully removed to small, marginal areas where the soil was poor. The apartheid state regulated the migration of workers from the bantustans to the farms, mines, towns and cities, and the residents’ opportunity to travel was severely restricted. For example, they were forced to carry ID documents that served as domestic passes that were required to move between ‘native reserves’ and ‘white’ urban areas (Bundy, 1977). In 1952 a national law was introduced which instituted a nationwide standard for such passes (the Abolition of Passes and Co-ordination of Documents Act). In Afrikaans, the passes were colloquially referred to as ‘dompas’, literally meaning the ‘dumb pass’. The new passbooks included a picture and fingerprint as well as information about race and employment details such as the name and address of the employer. This granted a right to spend time in certain white areas and settlements. The employer was also entitled to insert various comments about the person who carried the pass. There were employment programmes that facilitated migration, but women, children and ‘disabled’ men were generally excluded from these programmes (Legassick, 1977; Bundy, 1977). This restriction established socioeconomic inequalities which in turn influenced local interpretation and handling of afflictions and diseases. One consequence was

the creation of a divide between those who had access to medical technology and expertise, and those who did not have such ease of access.

Our understanding of disability may be seen as a consequence of society's dominant means of production. In British disability research, there is a key hypothesis that disability, in the modern sense, partly arose as a consequence of industrialisation (Oliver & Barnes, 1998). People were termed disabled when they were unable to work down the mines, in factories or in industrialised agriculture. Industrial workers emerge as a phenomenon as the focus shifts to employment and labour. The farm work of earlier eras and the needs of the extended family were replaced by the social field of interaction that was employment. This generated a divide between the able-bodied and the disabled which over time was internalised by the working and the non-working (Grue, 2010).

In South Africa, a division was established between the able-bodied and the disabled, and in part, this division coincided with the segregated settlement pattern and a labour market where 'disability' was often associated with *bantustans*. The division was founded on a view that people with disabilities were less competent than those who were able-bodied. This interpretation was internalised through a structural policy that accentuated segregation between the able-bodied and those who were considered 'disabled'. This classification meant that some types of bodies were defined as unfit for paid employment and education on the basis of age, gender and affliction (Hansen, 2015).

New disability policies: opposition to medicalisation

The disability policies that were devised during the post-apartheid period rejected the established historic dividing lines that were incorporated in the concept of employment. By focusing on *ability*, the makers of health policies aimed to redefine the 'able-bodied and productive' category. The new legislation established work as a legal right: everybody was entitled to employment irrespective of their gender and ethnicity.

Disabled People South Africa (DPSA) pioneered the re-formulation of capacity to work. Members with various functional impairments, who would previously have been classified as disabled but who were now either politicians or in paid employment, led by example and became role models. They demonstrated the competencies they had acquired through their impairments and showed that their experiences were relevant to many areas of policy that were important for creating inclusive structures in post-apartheid South Africa. One example is Max who was a member of the national assembly in Cape Town at the time I undertook my fieldwork. He was paralysed and a wheelchair user. When I met him, it was

very clear that he wanted to communicate the complexity of his own condition and the work he was doing in the assembly. He was a member of the transport committee and raised issues that demonstrated how he would be able to contribute to the world of work provided the material facilities were put in place. He used his job in the national assembly to raise public awareness of the physical obstacles he encountered in his everyday life, such as architectural designs that made it impossible for him to attend meetings. Max had been active in the anti-apartheid movement and a member of the African National Congress (ANC), and he was elected as a member of parliament. DPSA managed to negotiate representation by their male and female members in the new national assembly in Cape Town after the liberation in 1994 (Hansen.2015). Several members of DPSA had been key anti-apartheid activists and had been injured in the liberation struggle. From belonging to a group of people who previously would have been classed as 'disabled', they were now part of an elite who were tasked with creating the new South Africa. Creating new laws and policy among them the White Paper on an Integrated National Disability Strategy (1997), which shed light on the historic circumstances that had shaped people's understanding of self. The apartheid system had medicalised and institutionalised people with functional impairments and had therefore contributed to separating them from their family and local community.

Interests converged around the necessity of overturning the apartheid system and this created common grounds for people and groups who wanted change across established historic classifications, such as who was able-bodied and who was not. The disability policy conveyed the message that it was necessary to facilitate social and physical mobility for all. In addition to providing education, health care and social services for more people, it was considered important to ensure that public spaces and buildings were designed in a way that made them accessible to people with disabilities, to ensure that they would also be in a position to participate in politics, so as to better themselves. Participation in the world of work and politics was necessary in order to improve the living standard for the group as a whole.

Since 1994, new legislation has been introduced which affects who is categorised as able-bodied and disabled (the Employment Equity Act No 55, 1998; Promotion of Equity and Prevention of Unfair Discrimination Act No 4, 2000, 2003; and the Broad-Based Black Economic Empowerment Act 53, 2003). These laws highlighted the need for workplace adjustments and introduced a quota system which requires two per cent of the labour force to be disabled. The legislation re-defined 'the disabled' to become engaged individuals with a capacity to work and participate. The perspective on which the new laws were based, combined the natural and built environment with society and allowed history to set the

premise: decades of mobility restrictions, inequality of access to health and social care services, education, employment and political participation had produced physical, emotional, cognitive and social barriers that had to be swept away to ensure political representation and participation in the world of work.

Drafting the new laws also shed light on the general connection between place and participation in the world of work and politics. In reference to the former *bantustans*, the policy documents used the term ‘disadvantaged areas’, thereby highlighting the fact that the segregation and settlement policies of the apartheid era had established territories where basic needs such as electricity, clean water and the means of food production were non-existent. The apartheid policies created a particular form of poverty, where access to public services such as schools and health care, including institutions and medical expertise, was unevenly distributed, particularly in terms of the racial hierarchy and gender. Place names were used colloquially, but everyone was aware of the implications of *bantustans*. Anthropologist Didier Fassin (2003, 2007, 2008, 2009), who studies the social and cultural implications and consequences of epidemiological knowledge, points out that few health surveys were ever conducted in the former *bantustans*. One of the reasons was the lack of a properly developed public health service in the marginalised areas. In turn, this affected the population’s health as well as their interpretation and understanding of diseases, afflictions and the afflicted. Decades of segregation had left a bodily testament which continues to be acutely felt and which influences people’s interpretation and understanding of themselves in relation to others, even today (Fassin, 2007; 2009).

The new disability policy stressed that ‘disadvantage’ would have to be defined in a way that allowed the concept to incorporate the majority of the population, thereby making it possible for it to serve as a common starting point for reforms. The concept was linked to areas where the majority of the population lived. In this way, the living conditions offered by the disadvantaged areas were interwoven with bodily disadvantage. Disadvantage as a specific overall perspective on discrimination shaped the understanding, handling and classification of disability. The global disability rights movement concurs that there is universal segregation between people with impairments and the non-impaired. People with disabilities share the experience of being excluded from society. Just like the disability rights movement in South Africa, the international movement defines disability principally as a result of architectural, socioeconomic and cultural barriers, rather than as a result of mental or bodily deficiencies (Winance, 2010). The global disability rights movement argues that all people with impairments share a common experience of being excluded from full and equal

participation in majority society. A special feature of South Africa is that people with impairments share this experience with the majority of the population, who largely still feel excluded from equal access to participation and social recognition. The lines of demarcation are drawn on grounds of race, class, education and employment status; the majority of the population experience a 'disadvantage' in numerous areas of their lives, and people with a disability can therefore be said to be doubly disadvantaged. Understanding disability as discrimination is acknowledged in the new white paper on the rights of persons with disabilities (Gov. ZA 2015).

In the new South Africa, it has become important to create a new understanding of what disability is all about. Traditional local concepts and practices that focus on how people are construed through their relations and social standing, contribute to the generation of new forms of understanding. Various protective and healing practices, such as the *malopo* ritual that was performed for Kate, can be seen as arenas for the formation of new interpretations. During the *malopo* ritual, Kate's suffering was interpreted as a capacity and a talent for healing. Compared to the earlier classification system, this interpretation expands the boundaries of normality and demonstrates how people who suffer from 'convulsive states' have a position in a wider community: Kate's 'loose' body was caused by her relations with others, including the spirits of her ancestors, and could be 'strengthened' through these relations.

Ubuntu, society, person and disability

Reconciliation was an important aspect of the political shift after apartheid and also formed a shared foundation for addressing the *disability* issues. Reconciliation focused on humanism and inclusiveness. It is referred to as *ubuntu*, a word which translates into English as 'humanity'. *Ubuntu* was used as a conciliatory concept in the new Constitution: '[...] 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 of the Republic of South Africa, Act 200 of 1993: 251).

Richard Wilson (2013) argues that *ubuntu* is a humanist concept that represents rights, justice, reconciliation and nation-building within the language of Pan-Africanism. The word *ubuntu*, here spelt in Nguni, exists in all South Africa's languages. Its connotations include a humanism which explicitly links intersubjectivity to a perception of what makes a person a person in society, exemplified by a Zulu saying '*umuntu ngumuntu ngabantu*' or alternatively

a Xhosa saying '*umntu ngumuntungabatu*': 'a person is a person through other persons' (Tutu, 2012: 35). Antje Krog points out that *ubuntu* became key to the nation-building effort because it created a connection between human beings at a collective level (Krog, 2008).

According to Jean and John Comaroff (2009), *ubuntu* refers to community, a socially oriented sensibility and an ethos that has permeated public life in post-colonial South Africa. *Ubuntu* refers to a socially oriented sensibility where support, strength and assistance are internalised as a responsibility and a foundation for reciprocity – a norm for how to behave and act vis-à-vis other people. *Ubuntu* is therefore a form of interaction which is essential for becoming/being a social person; the self is formed in relation to others, and through interaction with them. Human as well as non-human aspects form a part of these fundamental relationships (Comaroff & Comaroff, 2009). This relational understanding lies at the heart of the new approach to disability and the local interpretations of afflictions. *Ubuntu* as a moral value and practice can create sensitising concepts and horizons of understanding with respect to afflictions and the afflicted, as well as recognition that health problems and healing are both consequences of the human condition and that healing is a process best achieved together.

The Truth and Reconciliation Commission (TRC) provides one example of how the *ubuntu* concept has been used in public life. The concepts of forgiveness, reconciliation, amnesty and justice were all conjoined in *ubuntu*. Desmond Tutu defined the concept in these terms:

It is the essence of being human. It speaks of the fact that my humanity is caught up and is inextricably bound up in yours. I am human because I belong. It speaks about wholeness, it speaks about compassion. 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. (Historyplex)

Nelson Mandela explained *ubuntu* as a relational concept which implies a responsibility to develop communities by sharing information and providing mutual moral support and advice in difficult situations. The *ubuntu* concept refers to local moral values and norms that are shared by the community and form a basis for a shared cultural understanding (Mandela, 2006).

Ubuntu is key to the disability rights movement, understood as intersubjectivity, transparency, shared moral values and standards, a shared cultural understanding and a responsibility for the development of society. This is exemplified by the policies promoted by Mr. Mavo and other politicians with impairments who sit in the national assembly in Cape Town. Their self-representation and candidness with respect to their own lives and experiences clearly show that they take responsibility for society and the development of a common and inclusive understanding of people with disabilities.

Terminology is important in politics. The South African Human Rights Commission emphasises that words and expressions should not be discriminatory or prevent the formation of a more inclusive society. They list a number of words they find to be unacceptable, terminology that *may* prevent a new understanding of *ability*, such as:

the disabled or the handicapped; crippled, suffers from, victim of; deformity or defect; wheelchair bound; normal; mentally retarded, brain damaged, slow learner; cerebral palsied, spastic/epileptic/paraplegic/quadruplegic; dwarf and midget; deaf and dumb (The South African Human Rights Commission, 2002: 9).

The Commission contributed to creating a moral-semantic field where terminology was actively used to change discriminating practices, and in today's South Africa the rule is for the person to come first, not his or her diagnosis or disability. Another example of semantic change is the wholesale replacement of the universal wheelchair sign, which signposts access routes for wheelchair users. In South Africa, this sign was interpreted by many as a personal characteristic rather than a description of accessible physical space. The sign was therefore replaced by the "expression physical challenges", an expression which refers to an environment without obstacles, designed in a way which allows universal physical mobility for all. 'Physical challenges' is not aimed at a specific group of people, such as wheelchair users, but describes a built environment where many different bodies can move freely around, using many different assistive devices and technologies.

Self-representation, *ubuntu* and poverty

According to Fassin (2007 and 2008), the past is still alive in the present; the existence of poverty, suffering and human degradation is part of the South African way of thinking. This mindset was also demonstrated in a research project carried out in a former 'homeland' territory (Hansen & Sait, 2011) where we conducted 58 interviews and organised ten village meetings. More than 100 people attended each of these meetings. The objective was to access people's understanding of the disability concept and of being a person with a disability. All interviewees and meeting attendees explained disability in terms of the environment and a shortage of care services, jobs, basic medication and treatment. Here are some examples of statements made in meetings and interviews:

- You are disabled when you can't do what you want.
- We can't find work
- 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 cost money and medication cost money, the distances are far.
- People here are experiencing pain, fits, illness and a body which can't do what they want.

The statements show that people talk about disability in public. They used the term openly, which in itself is interesting because it tells us something about the level of awareness that has been raised by the new disability policy – awareness of possible ways of talking about afflictions. The research team interpreted these statements to include an expression of expectations of the new regime.

All the above statements are underpinned by an awareness of how they, as individuals, are formed by their environment, and the word 'diagnosis', for example, is absent (see Hansen & Sait, 2011: 100-101). This demonstrates how collective processes can re-shape the understanding of what categories such as disability involves. The new disability concept includes poverty as a source of socioeconomic, social and political disadvantage. A shift in people's self-image is pivotal to this new understanding, allowing them to articulate their needs and expecting these to be recognised by other people. The statements express the

connections between social setting, living conditions and social standing, i.e. the relationship between society and the individual.

It was an important aspect of the study that so many people were able to congregate and talk about their experiences in association with perceived disadvantage/disability. This demonstrates *strength* and growing awareness of social stratification. Drawing on the *ubuntu* concept, we may say that collective experiences, when expressed, establish new moral communities such as those that are often formed to highlight important needs. I will go on to discuss how the presentation of personal needs by individuals/bodies/people has significant impact on whether or not a social security benefit is awarded, and that ‘convulsive states’ like those experienced by teenage Kate, are difficult to articulate and win recognition for in the social security system that was developed in the post-apartheid era.

Developing a social security system in the post-apartheid era

The social security system used to be available exclusively to white people, but it was extended in the post-apartheid era with the intention of providing cover for *all*. It is referred to as the *Comprehensive Social Security System* and formed part of a wider campaign under the *War against poverty* programme (<https://www.brandsouthafrica.com/south-africa-fast-facts/social-facts/poverty-280708>). The new social security system can be seen as a re-working of the original benefit and support categories which used to target poor women, the elderly and people with disabilities. From being available exclusively to white people, they were now made available to all (Giliomee, 2003). The heavy bureaucracy of earlier times was also retained. The aim was to develop a needs-oriented system that focused on particularly vulnerable groups such as children and people with disabilities, and people who depend on care, like war veterans and the elderly. Benefits were to be means-tested. Only the retirement pension for people over the age of 67 is universally awarded, i.e. neither needs-oriented nor means-tested.

The new social security system awards *disability grants* to people whose sensory, mental, physical and social impairments have been verified through medical examination and make you unfit to work for a period of longer than six months you can apply for disability grants. The grants are normally made payable for a limited period, but indefinite eligibility is deemed acceptable if the person’s condition is considered incurable. The monthly *disability grant* amounts to approximately ZAR 1.860 per month (SA. Gov. 2020). A multi-person household can live well on this sum of money, and in areas where unemployment is rife (near 60–70 per cent), ZAR 1.860 is essential for survival. Having access to a monthly income of

this magnitude changes a person's status within the household, because the individual with an impairment thereby becomes a breadwinner, capable of giving something in return for the assistance and care that he or she receives on a daily basis from other people in the household. Being the legitimate recipient of a pension, allowance or benefit can also contribute to a change in people's self-esteem, since they can now contribute financially to the upkeep of their household (Jelsma et al., 2008; Loeb et al., 2008; Hansen & Sait, 2011; Eide & Ingstad, 2013). The income also means that the household can take part in bartering arrangements with other households and share with other people. In this way, households where someone has a disability are also given an opportunity to take part in and initiate practices which ethically speaking are based on *ubuntu*; in other words, being able to give food and money to households or individuals who have no resources of their own. Such bartering arrangements facilitate reciprocity, which in turn strengthens a household's social security and status while boosting each of its member's general esteem within the local community (Hansen & Sait, 2011).

Mapping and classification within the social security system

The South African health authorities have implemented the World Health Organization's (WHO) *International Classification of Functioning Disability and Health* (ICF) as a standard, and this is the classification system that doctors use when they assess a person's disability. Consequently, the system's categories form the basis for the payment of benefits as well as the compilation of health statistics. WHO's ICF is an attempt to combine two models, the social and the medical, which represent polarised interpretations of how disability is explained and understood. Given its neutral cultural focus on individual levels of functionality as well as obstacles and barriers in the built and natural environment, participation is a core concept within this model. The traditional medical model defines disability as a result of individual, pathological and functional circumstances. The model focuses on institutionalisation and medical treatments which are intended to 'rehabilitate' the person. This medical model is seen in contrast to the social model which since the 1970s has been based on the view that people in special circumstances share a common experience of being excluded from society (Winance, 2010: 93). The disability rights movement in South Africa based their policies on this social model in order to re-define disability from being a quality associated with individuals to being a quality associated with the sociocultural and material surroundings.

The social model has been advocated by the UN since the 1980s through various rights programmes: the International Year of Disabled Persons in 1981 and Decade of Disabled

Persons 1983–1992. Among other things, this brought about the UN's *World Programme of Action Concerning Disabled Persons* and *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (UN, 1994). In the wake of these programmes, the UN's work on human rights saw a paradigm shift with the introduction of the *Convention on the Rights of Persons with Disabilities* (UNCRDP, 2006). In consequence, disability was now to be understood in the context of right to participation, where governments were expected to ensure that their citizens were given an opportunity to play an active part in all of society's arenas; in politics and the legislature, in health, education, sports, culture and leisure. This rights-oriented policy is founded on the idea that in earlier times, the planning of society erected barriers. In the future, governments will need to ensure universal access to the public arena and the material infrastructure, such as public buildings and public transport, and they have a special responsibility for ensuring that people with disabilities can operate on their own terms.

However, Kohrman (2005) maintains that the WHO classification system (ICF) takes a biomedical approach to the body which is based on the individual body's level of functionality – 'impairment of body functions and structures' (Kohrman, 2005: 29). The classification system does not relate to cultural variation in terms of body, nor to the various forms of subjectivity (Csordas 1994) and cannot therefore be considered to be culturally neutral, as first assumed. This means that the description of disability is determined on a biomedical basis, and consequently this also applies with respect to what is recognised and understood to be disability. Kohrman emphasises that bodily functioning and bodily structures cannot be given a culturally neutral interpretation and cannot therefore be disentangled from a relational context in which historic, social and political circumstances shape the body and experiences. Although the ICF model is advocated as being culturally neutral, it is still based on a biomedical understanding of the body as individual. It is therefore also possible to argue that even after apartheid, the South African authorities' mapping of disabilities and distribution of benefit payments, based on the WHO's ICF, implicate a disability perspective which is primarily found within a medicalised knowledge system.

The *Comprehensive Social Security System* which was developed in the post-apartheid era and which in principle was an extension of the system of that era and therefore the sole domain of white people, is still tinted by mixed perceptions of race, gender, disability and disease (Hansen & Sait, 2011). The social security system remains a financial support system which, like that operated during the apartheid era, is based on a divide between the employed and the unemployed, and aims to provide support for the 'disadvantaged', i.e. certain groups

are deemed vulnerable and will need extra financial support, thanks to their reduced capabilities. This may be considered to work against the more inclusive understanding of disability promoted by the disability rights movement. On the other hand, Amartya Sen (1990) argued for a disability concept that would compensate for the double need experienced by people with disabilities, so that their opportunities for social mobility are improved and they are in a better position to seek participation in society. Sen's interpretation of disability means that those affected need extra support. Being impaired entails being doubly excluded, and financial compensation is needed to put them in a position that allows them to make use of opportunities and appear as capable. This means extra funds which allow access to a doctor, medical examinations, assistive devices, school uniforms and transport. Only such additional compensation will create equality. In this context, the *Comprehensive Social Security System* may be seen to build on a capability approach rather than embodying an opposition to a more inclusive interpretation of disability. Following Amartya Sen disability grant should not only be linked to unfit to work but rather to the extra cost that need to be compensated in order to create equality and participations.

People are constantly being surveyed and assessed if they are in receipt of benefits, and assessments include the case officers' views on the benefit applicant's overall situation. Grue (2010) stresses that any award of welfare benefits must be based on medical grounds, and this involves an implicit or explicit suspicion that the person who applies for a benefit will try to cheat. This suspicion is felt as a bodily experience which shapes and is being shaped by conversations between doctor and patient and/or client and case officer. This is still the case in post-apartheid South Africa, and particularly in situations where *disability* must be assigned on the basis of a particular class of condition which triggers eligibility for benefit payments and the focus upon unfit to work. Hansen & Sait (2011) show that there are considerable local differences between assessments of what is eligible for benefit payments. Different areas follow different award practices. In rural parts of the Eastern Cape for example, there is disagreement about the definition of disability between medical experts and bureaucrats on the one hand, and applicants for benefit payments on the other. In the local community, this perceived unfairness means that questions are raised about the reasons why some are awarded benefits while others have their application rejected. This creates divisions and engenders jealousy. The feeling that benefits are unfairly awarded is also associated with the fact that in some communities, a great many people consider themselves to be disabled, in line with the new, wider and inclusive understanding of disability. In the villages, we frequently overheard talk of suspicion and mistrust associated with the selection process and

eligibility for benefit payments. This level of suspicion and mistrust was reminiscent of the discriminating social security system of the apartheid era (Hansen & Sait, 2011).

Conclusion: a third narrative about convulsions

Disabled People South Africa (DPSA) have advocated a definition and interpretation of disability which focus on physical / bodily impairments as a consequence of the sociocultural and material environment, where individuals with various *physical* sensory and mobility impairments have spearheaded the process through self-presentation, political representation and participation. The *by* organisations' advocacy has to a lesser extent included *cognitive* and *mental* sensory impairments and restrictions. Kate's story and narratives about other people with convulsions, spasticity and tremors have to a lesser extent been articulated in the public sphere by referring to the local notions of 'looseness' and 'strengthening'. Culturally speaking, 'convulsive states' have been included in emic normality concepts: an interpretation which is founded on the notion that human and non-human lives are interwoven. Within this conceptual framework, protection and healing are sought through a strengthening of relationships with those who are now deceased, the ancestors, in a context where collective processes that accentuate social relations strengthen each individual. During meetings and visits to various villages in the Eastern Cape, I have been struck by the widespread prevalence of convulsions and spasticity, and how the response of bystanders always demonstrates that this is within the realm of normality. I have observed many people who fall to the ground, some displaying more severe spasms than others, and how other people present immediately know what to do to assist: they put the person into recovery position, pop something under their head and wait for the convulsions to end before they accompany them home. This type of situation was a regular occurrence.

It is difficult to define 'convulsions' under the *Comprehensive Social Security System*. According to *Epilepsy South Africa*, it is a neurological disease, i.e. a medical diagnosis that can be established by means of medical technology. The organisations have made less of an effort to create an integrated understanding that assimilates different cultural frameworks. They have also made less of an effort to relate to the local conceptual framework for convulsive states, such as 'looseness' and 'strengthening', which are explanations that flourish in non-urban locations. *Epilepsy South Africa* have also not sought to establish whether convulsions are a result of living conditions. The interpretation of 'convulsive states' is not contextualised against poverty, the apartheid system and structural barriers. In the Eastern Cape, studies have been conducted on the connections between malnutrition,

unemployment and under-treatment of *neurocysticercosis*, a parasitic disease caused by *taenia solium* (the pork tapeworm), and which presents with seizure-like symptoms (34 602 of 54 000 registered cases in 2004 in the Eastern Cape, see Hansen & Sait, 2011: 106). However, no healthcare initiatives have emanated from these studies. Nevertheless, the considerable prevalence of convulsive states is also interesting in the context of what I was told and what I observed of convulsions during my two 12-month periods of fieldwork. Various physical, mental and cognitive conditions are considered capable of triggering ‘convulsive states’: HIV/AIDS, violence, birthing complications, malnutrition, unemployment, alcohol and substance use, to mention but a few.

The village population’s awareness of who and why someone suffered from convulsions caught my interest, particularly the differentiation between the two conditions termed ‘spirits in the head’ and ‘spirits in the stomach’ and how they were referenced and discussed in everyday life as good and bad periods. Even if the individuals in question opted to stay at home, people knew who suffered from convulsions. The people I talked to made a distinction between those who suffered only occasional symptoms of visiting spirits, and those who suffered persistent symptoms. This suggested that the spirits had taken permanent residence and that the body’s unrest and anger became increasingly worse, causing frustrations for family members and their neighbours. It is key that the local population’s challenges as they encountered these symptoms and afflictions, were not captured or highlighted by healthcare programmes run by central and regional authorities.

I studied 100 rejected benefit applications through the local organisation in the Eastern Cape and found that 70 of the cases were rejected because epilepsy was considered to be a treatable condition and did not therefore warrant payment of a disability grant – whether in the interim or as a permanent arrangement. However, the applicants could access free medication from local village healthcare clinics. The study shows that ‘convulsive states’ are not understood and explained locally as a disability covered by the social security system. Without access to the necessary medical technology and documentation of their affliction, it is difficult to gain recognition of convulsions as a persistent condition which might make you eligible for benefit payments. In the case of convulsions, it is also complicated for the afflicted to be heard by doctors and find acceptance for their perceived disease, particularly when this is described through the use of local concepts such as ‘looseness’ and ‘strengthening’. The fact that you have been seeking the help of a healer for years, does not appear in the health statistics and is not taken seriously by doctors, because healers are not recognised as medical experts by the public health service. There is no consolidation between

the two different medical systems, the state-run and the local. While formal medical treatment requires documentation, local protection and healing form part of an oral tradition.

Consequently, this lack of cohesion between the different health systems contributes to continued ‘disadvantage’ for many people in present-day South Africa. In this way, apartheid continues to exert a real and prominent impact today.

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References

Bundy, C., 1977, “The Transkei Peasantry”, in Palmer, R. H. & Parson N., (reds.), *The Roots of rural Poverty in Central and Southern Africa*, , London: Heineman,

Constitution of the Republic of South Africa, Act 200 of 1993: 251.

http://www1.chr.up.ac.za/chr_old/indigenous/documents/South%20Africa/Legislation/Constitution%20of%20South%20Africa%201993.pdf Lastet ned 2. april 2018.

Comaroff, J. & Comaroff, J., 2009, *Etnicity, Inc*, The University of Chicago Press., Chicago.

Comaroff, J. & Comaroff, J., 1987, “The madman and the migrant: work and labor in the historical consciousness of a South African People”, *American Ethnologist*, 14(2), 191-209.

Csordas, T., 1994, "Introduction the body as representations and being-in-the-world", in *Embodiment and experience the existential ground of culture and self*, Cambridge University Press.

Disabled People South Africa., 2001, *DPSA: An empowerment tool pocket guide on disability equity*, Cape Town: DPSA Parliamentary Office.

Eide, A. H., & Ingstad, B., 2013, "Disability and poverty-Reflections on research experiences in Africa and beyond", *African Journal of Disability*, 2(1), 1-7.

Fassin D., 2003, "The embodiment of inequality. Aids as a social condition and historical experience in South Africa", *Embo reports* 4: pp. 4-9. European Molecular Biology Organizations.

Fassin, D., 2007, *When Bodies Remember: Experiences and Politics of AIDS in South Africa*, University of California Press, Berkeley.

Fassin, D., 2008, "The embodiment of the past. From paranoid style to politics of memory in South Africa", *Social Anthropology* 16(3), 312-328.

Fassin, D. , 2009, "Another Politics of Life is Possible", *Theory, Culture and Society* 26(5), 44-60.

Giliomee, H., 2003, *The Afrikaners: Biography of a People*, Cape Town, Tafelberg.

Grue, J., 2010, *Kroppsspråk: Fremstillinger av funksjonshemming i kultur og samfunn*, Gyldendal Akademisk, Oslo.

Hacking, I., 1999, *The social construction of What?* Harvard University Press, Cambridge.

Hansen. C., 2001, *Fortellinger om annerledeshet. Et studie av barn med funksjonshemninger i Sør-Afrika*. Department of Social Anthropology. University of Oslo.

Hansen, C., 2015, *Ability in Disability. Disability practices in politics, organizations and bureaucracies in post-apartheid South Africa*. Ph.D., University of Oslo,

Hansen, C. & Sait, W., 2011, “We are also disabled: Disability Grants and poverty Politics in rural South Africa”, Eide, A. & Ingstad, B., (reds.) *Disability and Poverty: A Global Challenge*, The Policy Press, Bristol.

Historyplex: Understanding the Essence of Ubuntu - The African Philosophy,
<https://historyplex.com/ubuntu-african-philosophy> (23.03.2018.)

Jelsma, J., Maart, S., Eide, A., Toni M., & Loeb M., 2008, “Who gets the disability grant in South Africa? An analysis of the characteristics of recipients in urban and rural areas”, *Disability and Rehabilitation* vol, 30 (15): 1139-1145.

Kohrman, M., 2005, *Bodies of difference*, University of California Press. Berkeley, CA.

Krog, A., 2008, “This thing called reconciliation...'-forgiveness as part of an interconnectedness-towards-wholeness”, *South African Journal of Philosophy*, vol, 27(4), 353-366.

Larsen, K., 2008, *When Humans and Spirits meet. The politics of rituals and identified Spirits in Zanzibar*. Berghahn Books, Oxford.

Legassick, M., 1977, “Gold, Agriculture and Secondary industry in South Africa, 1885-1970.from Periphery to sub Metropole as Forced Labour System”, in Palmer, R. H., & Parsons, N., (reds.) *In The Roots of Rural Poverty in central and Southern Africa*, 175-200.London Heineman,

Loeb, M., Eide, A. H., Jelsma, J., Toni M., & Maart S., 2008, «Poverty and disability in Eastern and Western Cape Provinces, South Africa”, *Disability & Society*. Vol,23(4): 311-21.

Mandela, N., 2006, Web video of Nelson Mandela. Explaining the concept of Ubuntu. Accessed March 2013. <http://www.youtube.com/watch?v=Dx0qGJcm-qU>

Oliver, M., & Barnes, C., 1998, *Disabled people and social policy: from exclusion to inclusion*. Addison Wesley. Longman.

Sen, A., 1990, "Justice: Means versus freedom", *Philosophy and Public Affairs*. Vol, 19(2), 111-21.

South African Government, 1998, *The Employment Equity Act and The Code of Good Practice on Employment of Persons with Disabilities*

(http://www.info.gov.za/view/DynamicAction?pageid=545&sdate=1998&orderby=act_no_desc).

South African Government., 2003, *Broad-based Black Economic Empowerment Act*, no 5 (http://www.info.gov.za/view/DynamicAction?pageid=545&sdate=2003&orderby=act_no_desc).

South African Government, 2000, *The Promotion of Equality and Prevention of Unfair Discrimination Act* <http://www.justice.gov.za/legislation/acts/2000-004.pdf>

South African Government, 1996, *The Constitutions of Republic of South African* <http://www.gov.za/documents/constitution/1996/a108-96.pdf>

South African Government, 2020, Disability Grant. <https://www.gov.za/services/social-benefits/disability-grant>

The South African Human Rights Commission, 2002, *Towards a barrier-free society. What every South African should know about disability rights*. SAHRC.

Tutu, D., 2012, *No future without forgiveness*. Random House.

UN, 1994, *The standard rules on the equalizations of opportunities for person with disabilities*, New York: UN.

UNCRDP, 2006, *Convention on the Rights of Persons with Disabilities*. 2006. United Nations. Lastet ned 20.03.2013. (www.un.org/disabilities/default.asp?id=13&pid=150).

White Paper on an Integrated National Disability Strategy., 1997, Office of the Deputy President, T.M. Mbeki. South Africa.

White Paper on the rights of persons with disabilities., 2015,
<https://www.gov.za/documents/white-paper-rights-persons-disabilities-official-publication-and-gazetting-white-paper>

WHO., 2010, *International Classification of Functioning, Disability and Health*, ICF,
<http://www.who.int/classifications/icf/en/>

Wilson, R. A., 2001, *The Politics of Truth and reconciliation in South Africa-Legitimizing the Post-Apartheid State*. Cambridge University Press, Cambridge.

Winance, M., 2010, “Care and Disability Practices of Experimenting, Tinkering with and arranging people and technical aids”, in Mol, A. M., Moser, I., & Pols, J., (eds) *Care in Practice: on Tinkering in Clinics, homes and farms*. Transcript Verlag, 93-117. Bielefeld.