

**Do stories of people with disabilities matter?  
Exploration of a method to acknowledge the stories  
of people with disabilities as valuable oral  
sources in the writing of social history**

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*Abstract*

Oral history has been used as a valuable tool for the recording of the neglected history of the ordinary people. Since the 1980's, oral historians in South Africa have engaged recording the histories of the black people, the poor, the women, the children, migrant labourers and of the immigrants. What is glaringly absent from the recorded histories in the last thirty years are the voices of the people living with disabilities. This article attempts to propose a methodology on how oral history practitioners can go about recording the histories of people with disabilities. The article acknowledges the long history of cultural and religious discrimination, the lack of vocabulary and the education on how to understand the various disabilities and how best to record stories of people with disabilities in a non-prejudiced manner.

**Introduction**

The proposal of an oral history methodology for interviewing people with disabilities is informed by the fact that such people have been, as a group, left out of the mainstream oral history recordings as if they have no lived experiences. Although it is not excusable that their stories have been neglected, it is understandable why. The perceptions and ignorance about people with disabilities have contributed to the marginalization of their stories. That is despite the fact that oral history has been promoted both in academic and social circle as a tool that documents and record voices of ordinary people and as an alternative to a history written from above.<sup>1</sup>

To address the ignorance in an academic institution setting, an awareness campaign pamphlet from the University of KwaZulu-Natal entitled "What to say when you don't know what to say" gives guidelines on how to interact with people with disabilities. It states that,

People with disabilities are often marginalised within society and thus many people do not experience the opportunity of interacting and understanding their various needs. As a result, many of us are left feeling very uncomfortable around such people and will try to avoid them.

Such discomfort and the wish to avoid people with disabilities can be called a paralysing presence. Because one runs out of ways to interact as people without disabilities, one is paralysed in the presence of people with disabilities. Due to that paralysis caused by ignorance, we avoid contact. When contact is inevitable, people with disabilities are treated as children, as stupid or as incapable of transmitting their disabilities to anyone close-by. I have observed people adopting a slow or mono-syllabic speech form, using a loud voice or keeping a distance when interacting with people with disabilities. Although it is contestable whether or not the condition of albinism is a disability on its own,<sup>2</sup> it is interesting to note that the Tswana people have devised a way to immunize themselves against contracting the condition of albinism or at least not to give birth to a child with that condition. The practice when one is in an unavoidable presence with a person with such a condition is to spit on the ground and to touch or rub ones belly-button in order to fortify oneself against possible contraction of the condition.

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<sup>1</sup> Philippe Denis, "Introduction" in P. Denis (ed.), *Orality, Memory and the Past: Listening to the Voices of Black Clergy under Colonialism and Apartheid*. Cluster Publications: Pietermaritzburg. 2000, p.1.

<sup>2</sup> The University of KwaZulu-Natal awareness pamphlet calls albinism a condition and not a disability while a newspaper article titled "Albinism in Spotlight" by Victor Mecoamere of Sowetan wrote that, "Albinism is a broadly misunderstood condition that has recently been declared a disability by the United Nations." Sowetan, 6 September 2010, p.11. In the website of her Ministry of Women, Children and People with Disabilities, Minister Mayende Sibiyi took a simplistic position on this matter when she said, "Since albinism involves a visual impairment, it is thus considered a disability." Media Statement titled, *Minister calls for respect of rights of people with albinism*, 20 May 2010. [www.wcpd.gov.za](http://www.wcpd.gov.za) visited 4 October 2010.

After looking at why people with disabilities have been discriminated against we shall discuss in this article, who such people with disabilities are and if appropriate language can be used to de-stigmatize them. Finally we shall propose a method for oral history practitioners to explore when including in the mainstream stories of people with disabilities.

### Why the discrimination against people with disabilities?

For oral history practitioners to consider the value of stories of people with disabilities they need to understand the historical background to their discrimination and also find ways to work against those discriminations. To go blindly in communities that legitimize their stigmatization of people with disabilities on cultural and religious foundations can backfire and reinforce the stigmatization.

Our starting point is to find out what among the Sotho-Tswana is regarded as a person, *motho*. *Motho* is the basic unit of the human species that forms a Sotho-Tswana community, *sechaba* or *morafe*. For the sustenance of *sechaba* each unit, *motho*, has to make a contribution towards that end. There are a number of definitions of *motho* based on their expected contribution to the sustenance of *sechaba*. Some of the definitions divided along gender lines are: *monna ke kgomo* (possession of cattle indicates capacity to pay *lobola* and feed a family); *monna ke mosadi* (a proper man must have a wife), *monna ke bana* (a proper man must have children; sometimes the goal posts are pushed to expect one to have male children in order to qualify). Today the quality of a man is measured by his ability to earn a living and raise a family. Although initiation was a vital ritual as passage of life it has since lost its importance in the Christian era to measure entrance into true manhood.

A female member of *sechaba* found her worth through retaining her virginity until marriage, and then through childbearing, in order to become a *mosadi*. Besides childbearing, Sotho-Tswanas measured the worth and beauty of a *mosadi* by her industriousness as the idiom says, *mosadi tshwene, o jewa mabogo* (even if a woman can be as ugly as a baboon, she is still worth her salt if she is industrious). The Western world has different ideas of what makes a woman – and thereby a person. Among the Sotho-Tswana, any member who does not contribute to the sustenance of the community – mainly through labour-related activities like food-production and procreation – has her/his *botho*, personhood, questioned. Being less of a *motho* due to lack of expected active participation in the fundamental roles of “true persons” in the *sechaba* brings one exclusion and indignity. One remains a child without responsibility.

In order to further understand why people with disabilities are excluded from equal participation in the sustenance of *sechaba* let us consider what an African Theologian, Gabriel Setiloane wrote on how one becomes a *motho* in the *sechaba* among the Sotho-Tswana. He wrote thus about human beings and their *seriti/Isithunzi*:

Physically perceived the human person is like a live electric wire which is ever exuding force or energy in all directions. The force that is thus exuded is called ‘Seriti’ – ‘sithunzi’. *Seriti* has often been translated to mean dignity or personality. Actually, that only describes the end results of the phenomenon. It is derived from the same word-stem ‘-riti’ as ‘moriti’ – ‘umthunzi’ which means ‘shadow’, or ‘shade’. It is a physical phenomenon which expresses itself externally to the human body in a dynamic manner. It is like an aura around a human person, an invisible shadow or cloud or mist forming something like a magnetic or radar field. It gives forth into the traffic or weltering pool of life in community the uniqueness of each person and each object. While physically its seat is understood to be inside the human body, in the blood, its source is beyond and outside the human physical body.<sup>3</sup>

The vital force, or *seriti*, is found in varying degrees among the members of *sechaba* as Setiloane mentioned. Traditional healers like *sangomas*, due to their responsibility for the welfare of *sechaba*, are endowed with more intense *seriti* than ordinary persons. That is why then *sangomas* in a traditional Sotho-Tswana milieu have more dignity or personality than other people. As I argued with regard to the dignity given to productive men and women due to their productivity in the sustenance of humankind, health specialists have more *seriti* or dignity and personhood, because theirs is to sustain the productive forces of the men and women of *sechaba*.

People with disabilities who have deformities and can neither procreate to perpetuate human life nor participate in active farming to keep humanity going will by inference have a low dose of *seriti*. If

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<sup>3</sup> G. Setiloane, *African Theology: An Introduction*. Skotaville: Johannesburg. 1986, p.15.

*seriti* is what makes someone a *motho*, then people who do not participate in procreation and food production will be regarded in Sotho-Tswana categorizations as less than a *motho*, a human person.

People with deformities are seen not to have come out properly, that is to say, they were born with faults in their bodies. They therefore form a sub-group of people, called *digole* among the Tswanas. This categorization is meant to indicate that the people should be treated differently and not much productivity should be expected from their performance in the household life. Like children who are regarded as not fully human due to their lack of participation in procreation and life sustenance, people with disabilities are not expected to be different from children.

Is it possible that the coming of protestant missionaries to the indigenous people of southern Africa has contributed to the discrimination against people with disabilities, that is, through the Hebrew Bible where people with disabilities are marginalised?<sup>4</sup> Even in New Testament times people with disabilities were pushed to the margins of society and were not deemed to qualify ritually in the religion of Jahweh. The blind, the deaf, those with leprosy, the lame were all found outside the towns to beg or hope to be healed.

Negative and dehumanising attitudes towards people with disabilities can be changed first by learning about disabilities. The oral history practitioners whose discipline is subversive and unashamedly seeks to bring voices of the ordinary working men and women to the centre,<sup>5</sup> should engage in awareness campaigns to know and interact with people with disabilities.

### **Who are the people with disabilities?**

Firstly, as the name suggests, people with disabilities are people. They are individuals with names, feelings, aspirations and goals, fears and failures. Like all South Africans, they have experiences of joy and sadness. They have unique stories to share, that are based on their personal experiences. They may have disabilities, but that does not in anyway make them less human.

Secondly, disabilities vary. There are learning disabilities, physical disabilities, speech disabilities, psychiatric disabilities, hearing disabilities and many more. The causes of such disabilities cover a large variety. Similarly, the degrees of disabilities vary. If one is not aware of the causes and variations of disabilities, one is bound to adopt a one-size-fits-all approach in your interaction with people with disabilities and fail to make meaningful conversation as a result.

Some people were born with disabilities while others' disabilities were discovered later in life. Others became disabled in their adult stage. For those who were born with disabilities and those whose disabilities were manifested not long after birth, the relationship they had with their parents and people around them could have determined how to relate to strangers. Some may have been socialized to be ashamed of their disability, especially among strangers.

The devastation of parents at the discovery of the disabilities of their new-born babies, coupled with the responsibilities of bringing them up in an ignorant society is not easy to bear. They wonder how they could erase the disability in order for them to lead a manageable life. In a paper read at the International Oral History Association conference in Prague, in 2010, Noelle McComark argued that the optimism of the mother of the child with disability is viewed as unrealistic and overly emotional.<sup>6</sup> Writing about a mother who had to discontinue her dancing career to raise her child born with Rent syndrome, Noelle McComark refers to E Larson's *Reframing the meaning of disability to families: the embrace of paradox*.

The embrace of paradox was the management of the internal tension of opposing forces between loving the child as he or she was, and wanting to erase the disability, between dealing with incurability while pursuing solutions and between maintaining hopefulness for the child's future while being given negative information and battling their own fears. In the embrace of paradox, mothers created a positive bias and regained a sense of control that fuelled their optimism in their maternal work.<sup>7</sup>

Children with disability grow up with people who are ignorant both at home and in society. The parents want to erase the disability for their own sake, so that they could be able to raise the children. Although

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<sup>4</sup> Book of Leviticus Chapter One calls for various offerings but emphasizes that such offerings should be without defect.

<sup>5</sup> P. Denis, "Introduction" in P. Denis (ed.) *Orality, Memory and the Past: Listening to the Voices of Black Clergy under Colonialism and Apartheid*. Pietermaritzburg. 2000, p.2.

<sup>6</sup> Noellel McCormark, "Using oral history interviews to understand the experience of having a child who is profoundly disabled." p.2 (Paper read at the IOHA Conference in Prague, Czech Republic, 2010.)

<sup>7</sup> Elizabeth Larson, "Reframing the meaning of disability to families: The embrace of paradox" in *Social Science and Medicine* 1998, vol. 47, issue 7, pp. 865-875.

for oral practitioners the paralysis before a person with a disability is temporary for the duration of the interview relationship, for the parents it is a paralysis that can be overcome with the removal of the ignorance.

The Sotho-Tswana households that have family members with disabilities historically have had two ways of dealing with the situation of disability. They either hide their people with disability away from other people, especially strangers, as they would do with a big family scandal, or they treat them as children by not holding them responsible for their lives. When interviewed by Lucas Ngoetjana, a Tswana Indigenous Knowledge Systems specialist, Meiki Masuku had this to say about the people with disabilities and their role in society:

That the African family comprised of the entire village or community has been downplayed and undermined, and this has diminished the efficacy of the entire community as the caring community especially for vulnerable children and people. Within this context of caring, a person who had some of vulnerability was called: *Motho wa Modimo* ( a person of God). This person would also be called *Motho wa Kgobe* ( a person of God) in *Sotho-Tswana*. At times not in a misunderstood way diminutive sense, this person would politely be called: *segole* (a cripple), a person to be cared for even when that person was not a paraplegic (crippled). The word *segole* was used in a caring manner. This was one attitude that was displayed from childhood up to adulthood. At times and almost all the time when such a person does not follow socially and culturally acceptable norms and manners of public behaviour it was understood in a caring and not patronising way and they would be duly protected from suffering the consequences of the 'offence'. An African family is a completely caring village, Mama Masuku concurred.<sup>8</sup>

Since people with disabilities were not given responsibilities one can assume that they were treated as children and nothing good was expected to come from them. Writing about uninitiated Sotho-Tswana children and their responsibilities Breutz said, "An uninitiated 'child' is not responsible for its actions under tribal laws."<sup>9</sup>

People who have been excluded from responsibility from childhood without critically determining whether or not they were capable may not find it easy to take responsibility. Oral history practitioners wishing to interview people with disabilities have a lot to learn. It will need a lot of effort and patience to gain the trust of a person who has not been appreciated for who they are.

Culture and ignorance have so far dictated how the Sotho-Tswana and even cultures of the west have had to relate to people with disabilities. In South Africa the number of people with disabilities is increasing in the public domain. Depending on their disabilities, special schools have provided education and training to people with disabilities, allowing them to participate in the obscured margins of society. If we note that disabilities vary in intensity and that physical disability does not necessarily have a bearing on intellectual capacity, we as oral history practitioners will recognise the agency of people with disabilities and record their stories. Because people with disabilities are differently-abled, we cannot assume that we can interview them just as we interview everybody else. We need to learn how to relate to them in an acceptable manner.

### **Language and terminology**

Language is the key to respect. Oral history practitioners who have to interact with people with disability have a responsibility to learn how to speak respectfully with them. For mutual understanding, oral historians have to find and learn ways and means of communication. If they assume that the interviewees have to conform to their jargon there will be a communication breakdown.

In an interaction with people with disabilities like with all other interviewees, it is important to show respect to them and treat them with dignity. It has been shown that the language one uses in talking to others can tell whether one relates to them with respect or with disdain. Both in race relations and gender relations there have been discussions where those who felt marginalized rejected some categorizations in favour of others. In South Africa black people have rejected categorizations like natives and Bantus in favour of blacks. Today one is careful to use the term "coloured" because some people prefer to be referred to as "so-called coloured" or "brown people." Feminists have rejected a term like "lady" in favour of woman. They also rejected a title like Miss or Mrs in favour of Ms.

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<sup>8</sup> Lucas Ngoetjana, *The Legacy of Mama Grace Meiki Masuku: An Embodiment of African Heritage*. North West parks and Tourism Board: Mafikeng. 2007, p.52).

<sup>9</sup> P.L Breutz. *History of the Batswana*. Dr. P.-L. Breutz: Ramsgate.1989, p.63.

Trivial as it may seem, incorrect categorizations have been used to exclude, insult and dehumanise sections of South African society.

The University of KwaZulu-Natal pamphlet gives examples of terms to be avoided at all costs in reference to people of various disabilities, viz. “deaf and dumb” for people who are deaf or hard of hearing; “cripple” for a person who is wheelchair-bound; “paraplegic” for a crippled person; “albino” for a person with albinism or with a condition of albinism. While these terms help to understand the situation of people with disabilities, they are not substitutes for the individual names that each person has.

### **Proposed methodology**

Oral historians need to be reminded what their purpose is. Although oral historians are encouraged to empathise with interviewees in their situation of distress, they are not to pretend to be authorities on any form of therapy if they are not trained in the field of counselling. Critiquing the mandate and capacity of the Truth and Reconciliation Commission of South Africa to bring about the healing of the victims of violence and their relatives, Sean Field dissuades oral historians from pretences of providing healing to interviewees. He wrote, “Simply put, I do not think oral historians should make claims ‘to heal’, especially when interviewing trauma survivors.”<sup>10</sup> An oral historian is interested in the life stories of the interviews as told by them or by people who know them. One needs to bear in mind the fact that people with disabilities have been taken to therapist who have helped them to live with their disabilities. To give them false hope on changing their disability will not help the relationship or the interview.

The best methodology is the one discussed with the potential interviewee. Due to the various forms of disabilities and their intensities, the methodology will differ from one interviewee to the other. The interviewer should not assume anything regarding the method of interview.

Having lived their lives in a society that marginalises them, people with disabilities, like all the marginalised, would feel affirmed when asked to tell their stories. Amongst the three purposes of oral history mentioned in the Sinomlando Research Centre for Oral History and Memory Work in Africa there is a developmental one. Unlike the other two, the developmental purpose values both the process of the interview as well as the product. The interview is not only aimed at acquiring information to fill the gaps in history books or to train pupils how to use technology when recording an interview. The interview grants the interviewees an opportunity to take the position of the subject and to remember, construct and tell their stories as they wish.

It is crucial to follow what Sinomlando’s training manual recommends as conditions of the interview.<sup>11</sup> Although not necessarily directed to the interviewing of people with disabilities, it is just as important to be considered when interviewing people with disabilities. The conditions of the interview consider things like place of interview, other people who will be present during the interview, preferred language or mode of communication, what will happen to the interview and who will have access to it, release agreements and informed consent.

If the interviewee with a disability has a communication barrier and has a challenge in using everyday speech or is hard of hearing, the interviewer in partnership with the interviewee has to find a way to bridge the communication gap.

### **Hearing and speaking disability**

If one is not taking it as a career to interview people with hearing and speech disability, one can opt for using an interpreter versed in sign language. Just like other people, people with hearing and speech limitations have friends and relatives who communicate with them on regular basis and can assist in the planning and preparation stages of the interview. By agreement the same interpreter can be asked to help during the interview encounter itself. Pen and paper or Braille orthography can bridge the communication gap. The UKZN pamphlet gives advice on how best to relate to people who are deafened or hard of hearing. Some of the tips can be helpful and will show the potential interviewee the seriousness of the intention to learn from them.

Gently tap a person on the shoulder if he/she is not facing you.

Never yell or exaggerate your speech – speak your normal tone of voice.

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<sup>10</sup> Sean Field, “Beyond ‘Healing’: Trauma, Oral History and Regeneration”, in *Oral History*, 2006, Vol.34 No.1 pp.31 – 42.

<sup>11</sup> [www.sinomlando.org.za](http://www.sinomlando.org.za) see the oral history training manual.

Use alternate communication methods if necessary – ask what method is preferred e.g. pen and paper.  
Look directly at the person and speak clearly, without anything in front of your mouth (e.g. cigarettes).  
Do not make assumptions about level of intellect or hearing.  
Do not show impatience. Communication for deaf people is different because their first language is Sign Language.

In counselling sessions with a woman called Lintle, Christina Landman found a pen and paper method very helpful in breaking the communication barrier:

By the time we were moving into the alternative story, I was despairing of the process. Verbally, Lintle was communicating with great difficulty. Since Lintle was reading with more ease than she could speak, I wrote on a piece of paper: Lintle is a survivor. Also, I wrote a report for Lintle's file. This file was filled with reports from doctors to occupational therapists to psychologists about Lintle's disabilities. In my report I wrote that Lintle was a survivor. I substantiated with parts from our "conversation" about Lintle's ability to survive her present circumstances. I gave the report to Lintle to read. Her face brightened up.<sup>12</sup>

Lintle, according to Landman, came back for therapy after two weeks a completely changed person. She wanted to go back to school and also to prove that she was not stupid.<sup>13</sup>

In a similar manner, when one's potential interviewer is someone who is blind, negotiations are necessary in order to avoid false or conflicting expectations. Since the eyes of blind people are their hands, anyone interviewing a blind person must prepare themselves to be touched. Trust between the interviewer and the interviewee is a pre-requisite for a rich interview. The blind interviewee can be allowed to touch the recording instrument in order to make the interview situation as less foreign and less sophisticated as possible. For a person who cannot see it is important to explain as much as possible how the process will go for them to relax and not be distracted by the clicking sounds from the recording and cameras. Minimize things that you will bring to the interview place so that the interviewee can concentrate on the interview rather than the many new things that will change the setting in the place of the interview.

The UKZN pamphlet is helpful as it gives general "do's" and "don'ts" tips in interacting with people with visual impairments. Some of them are:

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<sup>12</sup> Christina Landman, *Township Spiritualities and Counseling*. Unisa Press: Pretoria. 2009, p.98.

<sup>13</sup> Landman, 2009, p.98 – 99.

- Do not assume the person cannot see you.
- Identify yourself and others when you approach.
- Never touch a person without warning, unless it is an emergency.
- Ask if help is needed, and if so HOW you can best help – DON'T make assumptions.
- Never distract a guide dog without its owner's permission.
- Look at the person when speaking.
- Do not leave the person in the middle of the room – show them to a chair, and guide them to its edge.
- If conversing in a group, remember to identify to whom you are speaking.

### **Beyond the stereotype boundaries**

The recognition that people with disabilities are full human beings with lived experiences can serve as a guide to help oral historians to acknowledge some of them as important informants in research. The people with disabilities are intelligent person and may exercise their right by refusing to have their stories recorded. To seek an interview with a person with disability is not doing him or her any favours. It is the interviewer who seeks information from the interviewee. When such an interview is granted, it is important to know that the interviewer remains in the mercy of the interviewee to complete the interview.

In interviewing people who have been forced to be in the margins for many years the interviewer has to note that the interviewees may construct and tell their stories their own way. Most of them will acknowledge the interview as an affirmation of their humanity. As a result the interview may gravitate towards the direction they choose.

One can never be sure how an interview will produce, that is, to what type of product it will lead. Since interviewing people with disabilities can be done both for academic and developmental purposes, the interviewer must value the process as equally important as the product. The interviewee should at the end of the interview feel that the exercise was worth it.

It is pointless to have stories from people with disabilities without critiquing them as real oral text stories. As stories of human beings we should assume that like other interviewees, people with disabilities have reasons why they want to tell their stories.<sup>14</sup> We have to use tools to enquire why the story is told the way it is told, what gender issues are at play in telling the stories, what things are deliberately omitted or added in the telling of the story, what trauma can be detected, what historical continuities and discontinuities are present in the story, what type of story is constituted, that is, whether it is a press release or story from the heart, and what the quality of memory is.

### **Conclusion**

This article attempted to show how the Sotho–Tswana culture has through ignorance excluded people with disabilities from active participation in the life of their communities. The same ignorance is found among the oral history practitioners who have neglected stories of people with disabilities. This article suggests a methodology of interviewing people with disabilities firstly learning the acceptable language that shows respect to people with disabilities and does not perpetuate discrimination. Secondly the article suggests that due to the different disabilities and their varying intensity, oral history practitioners need to avoid assumptions and stereotypes by asking the best way to interact with people with disabilities. As users of a method of history that does not hide its subversive approach to write histories of the marginalized, oral historians are challenged to cross the lines of their comfort zones and record stories of people with disabilities and learn from them just as they have been learning from stories of other people.

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<sup>14</sup> R. Ntsimane "Why should I tell my story? Culture and Gender in Oral History" in P. Dens and R. Ntsimane (eds.) *Oral History in a Wounded Country: Interactive Interviewing in South Africa*. University of kwaZulu-Natal Press: Pietermaritzburg. 2008, p.125.

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