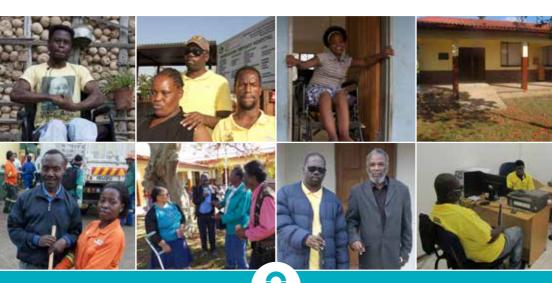# CREATE
CBR Education and Training for Empowerment

Disability Inclusion:
Possibilities
and **Progress**

A Case Study in uMfolozi Local Municipality,
KwaZulu-Natal, South Africa

OXFAM

ACKNOWLEDGEMENTS

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South Africa

June 2014

CONTENTS

Case study participants' memories and perceptions

1950

- People with disabilities were not regarded as human beings.
- They were excluded from the rest of the family.
- They were kept in isolation.
- When there were gatherings in homes people with disabilities would be locked away so that the others in the household would not be embarrassed.

1960

- People with disabilities were not involved in community activities like ward meetings.
- There was a divorce in a family because a wife gave birth to a disabled child.
- Disabled black people had no assistive devices; some were dragged around.
- There was discrimination against people with disabilities by their families and community members.
- There were no organisations for people with disabilities.
- People with disabilities were regarded as a punishment (to their parents and families).
- People with albinism were also regarded as a punishment and there was a belief that they were immortal.
- People with albinism were called monkeys; some parents did not allow children with albinism to attend school.
- In rural areas disabled children had limited opportunities to go to school.
- Non-disabled women did not want to have relationships with disbled men as they believed that the children from these relationships would be disabled.
- People with disabilities were laughed at and mocked.
- Some men sexually abused women with disabilities in the sugar cane fields; in some places this still happens.

1970

- Black people with disabilities were not eligible for monthly grants.
- People with disabilities were discriminated against by their families.
- A person with a disability was expected to use his or her own spoon, plate and cup, and these utensils were washed separately.
- Some mothers of disabled children did not love and support their children.
- Mothers of disabled children faced emotional difficulties and abuse from their families, so they hid their children. These problems continue to this day.
- Mothers of children with disabilities carried the blame for giving birth to them.
- Witchcraft was believed to cause disability and this belief persists.
- Some people believed disability was a gift from God or from the ancestors, and this belief also persists.

- People began conducting disability awareness on radio and through this people began to hear about disabled people's organisations.
- Some people with disabilities became members of the ANC.
- Some disabled children living in townships were placed in special schools.
- Children with disabilities living in rural areas stayed at home and did not go to school.
- Most disabled people believed that their entire lives were about disability.
- People with disabilities felt that they were not supposed to exist; they were waiting for their day to die.
- One disabled person drove a car – using a stick to reach the pedals.
- Gradually children with disabilities began to attend 'normal' schools.
- There was still discrimination against people with disabilities by churches.

1980

- Disabled People South Africa mobilised disabled people in rural areas.
- Disabled people's organisations were formed.
- Education opportunities for people with disabilities were introduced and people with disabilities attended various training workshops.
- Black people with disabilities became eligible for monthly grants.

1995

- Disabled people have developed a better understanding of their rights.
- uMfolozi Local Municipality has allocated money in its budget specifically for matters related to people with disabilities.
- People with disabilities are included in ward committees, Sukuma Sakhe and other community structures.
- uMfolozi Local Municipality provides an office for people with disabilities and Richards Bay Minerals provided the furniture for the office.
- People with disabilities are employed by the Expanded Public Works Programme (EPWP).
- People with disabilities own small businesses.
- People with disabilities actively participate in politics.
- One person with a disability is a member of a traditional council.
- A chief gave people with disabilities a piece of land to use.
- People with disabilities have their own RDP houses.
- There are pastors and church elders with disabilities.
- People with speech impairments still experience lots of discrimination, including from their families and community members.

After 2010

Location of uMfolozi Local Municipality within the context of uThungulu District Municipality and the province of KwaZulu-Natal

Notes on the terminology used

In this document, CREATE uses "people first" terminology i.e. person with a disability rather than disabled person. We believe that we need to see the person before the disability. This terminology is also in line with the United Nations Convention on the Rights of Persons with Disabilities (2006), which has been ratified by South Africa.

In South Africa there are both district and local municipalities. A district municipality consists of a number of smaller, local municipalities. In KwaZulu-Natal there are 11 district municipalities and 51 local municipalities. This case study was conducted in uMfolozi Local Municipality which falls under uThungulu District Municipality.

Abbreviations

CBR	Community Based Rehabilitation
CREATE	CBR Education and Training for Empowerment
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DPO	Disabled people's organisation
EPWP	Extended Public Works Programme
IDP	Integrated Development Plan
LRC	Legal Resources Centre
NGO	Non-governmental organisation
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PRA	Participatory Rural Appraisal
SASSA	South African Social Security Agency
UN	United Nations

Among the yardsticks by which to measure a society's respect for human rights, to evaluate the level of its maturity and its generosity of spirit, is by looking at the status that it accords to those members of society who are most vulnerable, disabled people, the senior citizens and its children.

T. M. Mbeki (1997) Integrated National Disability Strategy

SECTION 1: INTRODUCTION

The World Report on Disability (2011) describes disability as both a human rights issue and a development issue. According to this report, it is a worldwide phenomenon that people with disabilities experience discrimination and inequality and that they are disproportionately represented amongst the poor.

As mentioned by former South African President Thabo Mbeki, people with disabilities are also particularly vulnerable, to stigma, marginalisation, neglect, abuse and other social problems. The Integrated National Disability Strategy and more recent publications document some of the barriers experienced by people with disabilities in South Africa. For example, negative attitudes towards people with disabilities can affect those people's access to mainstream services such as education, transport and housing, while inaccessible communication may be due to the lack of sign language interpreters, Braille documents and alternative and augmentative communication devices. In addition, many public buildings remain inaccessible to people with disabilities because they lack such things as ramps, accessible toilets and wide doorways.

We have undertaken the research required to produce this case study in a rural municipality and traditional authority where we believe many strides have been made in recognising the rights of people with disabilities and where progress has been made with respect to the inclusion of people with disabilities into mainstream society and community life. We previously conducted disability training in 10 of the 11 districts of KwaZulu-Natal, and subsequent to this training, the uMfolozi Local Municipality attracted our

interest because it became evident that the Disability Forum in that area had sustained its work to improve the situation of people with disabilities. This study set out to explore the reasons for the sustained progress that uMfolozi Local Municipality and KwaSokhulu Traditional Authority have made in disability inclusion in their geographical area. It is our hope that the lessons shared in this case study may help to inform the development of a disability-inclusive society throughout South Africa.

1.1 Who is CREATE?

CREATE is a registered non-profit organisation in KwaZulu-Natal that was established in 2001. CREATE's vision is to be a sustainable, independent, reflective, rights-based organisation that makes a difference in the lives of people with disabilities through supporting individuals and promoting an inclusive society.

CREATE's main areas of engagement include working with other mainstream non-government organisations (NGOs), for example, NGOs focusing on water and sanitation or gender-based violence, to build their capacity to include people with disabilities in their projects and services; advocating for the respect of the rights of people with disabilities with different groups, such as traditional leaders and municipal and government officials; developing the skills of young people with disabilities to enter the world of work or to generate an income in another way; and providing training for various types of personnel on disability, rehabilitation and community based rehabilitation (CBR). CREATE works with disabled people's organisations (DPO), communities and government departments to advocate for implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD). CREATE also engages in various research projects concerned with disability, CBR and disability rights.

1.2 Introduction to uMfolozi Local Municipality

uMfolozi Local Municipality is one of the six local municipalities that fall under uThungulu District Municipality. The vision of uMfolozi Local Municipality is to improve the quality of life of all the people in its municipality by creating economically viable development. The mission of uMfolozi Local Municipality is to strive towards providing services that will meet the needs of all people by promoting social and economic development, providing and maintaining affordable services, efficient and effective utilisation of resources, marketing the municipality locally and globally and establishing the municipality as a tourist destination. There are three Traditional Councils within uMfolozi Local Municipality: Sokhulu Traditional Council, which is led by iNkosi[1] Mthiyane; Mbonambi Traditional Council, which is led by iNkosi Mbuyazi; and Mhlana Traditional Council, which is led by iNkosi Mthethwa.

uMfolozi Local Municipality represents a rural area where much of the land belongs to the Ingonyama Trust Board and is controlled by the three traditional authorities mentioned previously. The area borders on the Hluhluwe-iMfolozi Park (formerly Hluhluwe-iMfolozi Game Reserve). As at 2011, the unemployment rate was 42% amongst the population of 122 900 people (Census 2011). Only 10.5% of the population have piped water inside their dwellings although 83.7% have electricity for lighting. With regards educational levels amongst adults (over 20 years of age), 30.3% have passed Grade 12 while 14.6% have had no schooling at all. The Census 2011 data on people with disabilities relate only to disability prevalence; unfortunately more detailed information has not yet been made available.

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1 *iNkosi* is the *isiZulu* word for chief (in this instance this is a reference to a named chief, so the letter N is capitalised)

SECTION 2: UNDERSTANDING DISABILITY IN SOUTH AFRICA

In many countries the understanding of disability has changed over time, moving from focusing on the problems and deficits of the individual, to perceiving disability as a human rights issue and a problem of society not coping with diversity. These different conceptualisations of disability are known as the medical and social models of disability and still frequently co-exist in one country.

2.1 The Medical and Social Models of Disability

Within the medical model, the focus of disability is very much on the individual, specifically on the body or an "impairment" of the body. This view was encapsulated in the World Health Organisation's International Classification of Impairment, Disability and Handicap (ICIDH-1, 1980). It defined disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range considered normal".

The medical model relies on a strong notion of "normality" and perceives disability as "deviant functioning of the body", which needs to be "corrected" (for example, by performing cochlear implants rather than the person learning and using sign language). In terms of rehabilitation the emphasis is on removing the impairment for the benefit of people with disabilities and

for society. Assumptions are therefore made that disability and impairment are automatically associated with poor quality of life.

Another of the underlying values of the medical model is that disability is perceived to be a "sickness" or "personal tragedy". From these perceptions different opinions are then made about people with disabilities, that is, that they are limited in function and role performance. According to Coleridge (1993), this in turn has led to people with disabilities being underprivileged and ignored in their local communities and also being treated as or considered to be "objects of charity".

From the 1970s, the disability rights movement began to argue that the "problem" of disability can be addressed through the restructuring of society and not through "normalisation" or cure as in the stance held by the medical model. This viewpoint formed the basis of the social model, which perceived disability as the result of any behaviour or barrier in society that prevented people with a disability or impairment choosing to play an equal part in life (Oliver, 1993).

When looking at disability as a socially created construct, people with disabilities speak of the barriers that society creates. These barriers may relate to attitudes, environmental accessibility, communication, policies and finance, amongst others. Thus, for example, a person who is blind may be disabled in a tertiary education setting not because of visual impairment but because of the lecturer's omission to explain what is appearing on the slides of a projected visual presentation during a lecture. Similarly, a person who uses a wheelchair is disabled by the negative attitude of a taxi driver who charges an additional fare for the wheelchair.

The social model of disability is also closely aligned to the human rights perspective of disability, which understands that people with disabilities

have the right to dignity, equal opportunities and a range of civil, political and socio-economic rights. In this perspective of disability, the problems that people with disabilities experience in society are often seen as violations of their human rights.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was developed to specifically address the implementation of rights for people with disabilities. The purpose of the CRPD is to "promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity".

2.2 Disability perspectives in South Africa

In South Africa, there has been a shift to the social model and an understanding of disability as a human rights issue at an official government

level. This is reflected in the South African government's adoption of the Integrated National Disability Strategy (INDS) in 1997 which is based on the premise that society is the barrier to political, social and economic emancipation for people with disabilities. In November 2007, South Africa also ratified the CRPD and its Optional Protocol, and it subsequently entered into force in South Africa on 3 May 2008. South Africa is therefore required to ensure that consideration of disability is included in all legislation and that discrimination against people with disabilities is eliminated.

In South African society, however, there are still many people and communities who view disability as a personal tragedy and who think that people with disabilities cannot participate in society, but should simply receive disability grants from government. In some places this attitude is even prevalent at local municipality level. For example, a disability focal person[2] in local government may organise nutrition support (in the form of "food parcels") for families that include a person with a disability, thus engaging in dispensing "charity", while not addressing such things as the right of people with disabilities to be able to gain access to municipal buildings and public spaces. Similarly, through its work in communities across KwaZulu-Natal, CREATE has been witness to many examples of people with disabilities not being thought of as "normal" and therefore not able to participate in activities as "normal" people. Examples of this are several incidents that CREATE staff have experienced where adult people with disabilities were forced to be accompanied by their parents in order to be allowed access to HIV testing and counselling.

2 A disability focal person is a person designated by a municipality to deal with disability issues on behalf of the municipality. Often this person has responsibility for other vulnerable groups, such as the elderly.

2.3 Disability and disadvantage in South Africa: some facts and figures

Disability data at a glance

7.4% of South Africans over the age of five have a disability (Census 2011)

8.2% of the population in KwaZulu-Natal have disabilities (Census 2011)

At the end of 2012, **1 180 063** people received disability grants (some of whom have AIDS-related conditions rather than a disability)

In 2012, **16.7%** of people with disabilities were HIV positive, the third highest at risk group in South Africa

74% of households in KwaZulu-Natal headed by a non-disabled person had access to piped water whereas only **62%** of households headed by a person with a disability had access to piped water

0.9% of the South African workforce in 2013 was made up of people with disabilities although the Employment Equity Act sets a target of **2%**

Education White Paper 6 (on Special Needs Education) estimated that approximately **280 000** children with disabilities who were of school-going age were unaccounted for within the school system in 2001

All figures are taken from the latest information available as at June 2014

SECTION 3: LOOKING MORE CLOSELY AT UMFOLOZI LOCAL MUNICIPALITY

In this section we take a closer look at the experiences of people with disabilities in uMfolozi Local Municipality and KwaSokhulu Traditional Authority, to see how life has changed for them and to explore why people feel this has happened. Initially we describe how CREATE has been involved in this area over the past three years. We explain the methods CREATE used to gather the information for this case study and then detail what we found.

3.1 CREATE's involvement regarding disability in uMfolozi Local Municipality

CREATE, the Legal Resource Centre (LRC) and the Office of the Premier of KwaZulu-Natal jointly ran two four-day training workshops for human rights forum members in 10 districts of KwaZulu-Natal. Two Disability Forum members from uMfolozi attended this training in uThungulu District. Module 1 of the training covered topics such as the Constitution of South Africa, including the Bill of Rights that is set out in the Constitution, the CRPD and different responsibilities of government at the national, provincial and local levels. Module 2 of the training focused more specifically on the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) and the

Equality courts. In 2013, CREATE developed and ran training workshops for traditional leaders in KwaSokhulu and Ntambanana (an administrative area in uThungulu District). The training focused on understanding disability and then looking at how people with disabilities can access justice in the traditional courts.

Subsequent to the training, CREATE also provided the following services to members of the Disability Forum:

- After the module 1 and 2 training, the forum members were supported telephonically when they needed help, for example, when they needed clarification on aspects of the CRPD and PEPUDA.

- The matters that needed legal advice were referred to the LRC.

- The challenges that arose due to the unaccommodating attitudes of some senior officials were referred to the Office of the Premier, with requests for advice.

- The Office of the Premier provided information on Operation Sukuma Sakhe.[3] This was pivotal because the forum members were then able to meet with the senior government officials involved in the operation to discuss the violation of disability rights and other human rights.

- CREATE, the Office of the Premier and the LRC attended the events arranged to launch Sukuma Sakhe and made brief presentations regarding the content of the disability training that had previously been provided.

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3 "Operation Sukuma Sakhe (OSS) is a provincial programme that was founded on the premise of taking government to the people in a coordinated manner. 'Sukuma sakhe' is a Zulu phrase which means stand up and build. The programme has been launched in all 11 district municipalities and 51 local municipalities under them." (Page 2, Operation Sukuma Sakhe Guidelines)

3.2 How CREATE gathered information for the case study

CREATE identified a number of key stakeholders either concerned with disability or affected by disability in uMfolozi Local Municipality and KwaSokhulu Traditional Authority. These stakeholders were the chairperson of the Disability Forum, parents of children with disabilities, adults with disabilities, the disability focal person in the uMfolozi Local Municipality, the head of the Community Services Department in the municipality and traditional leaders from KwaSokhulu Traditional Authority (including *izinduna*[4] and *amaphoyisa*[5]). CREATE ensured that people with a range of impairments were included – there were people who were blind, others with physical impairments, people with epilepsy, one person who had a speech impairment and one person who had a hearing impairment. In addition, mothers of children with intellectual impairments, epilepsy, hearing impairment and visual impairment also participated.

Because we wanted to find out in detail about people's perceptions, we used methods of gathering information that would give them a chance to talk freely. We conducted semi-structured interviews with the two municipal officials and the chairperson of the Disability Forum. We held focus group discussions with two groups of traditional leaders, and a further two focus group discussions with parents of children with disabilities and adults with disabilities, from two different areas. In order to get a sense of the length of time it took for positive changes and developments to occur in uMfolozi, we used participatory rural appraisal (PRA) to draw up a timeline. The people who participated in the PRA were all either an adult with a disability or a

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4 *izinduna* is plural for *induna*, the *isiZulu* words for headmen and headman respectively

5 *amaphoyisa* is the *isiZulu* word for community police

parent of a child with a disability. Some of these participants had also been part of a focus group discussion.

Two of the three interviews, all the focus group discussions and the PRA session were conducted in *isiZulu*. Where necessary, a family member interpreted into sign language for a hearing-impaired participant. With permission from the participants, each interview, focus group discussion and the PRA session were audio-recorded then transcribed and translated into English.

3.3 The current situation of people with disabilities in uMfolozi Local Municipality

The participants in this case study spoke about the many different positive aspects of the lives of people with disabilities in uMfolozi Local Municipality although this was tempered with their reports of a number of challenges they experience as well.

People with disabilities described themselves as empowered, able to speak up for themselves and able to question government departments. They reported being aware of the rights afforded them by the Constitution, CRPD and PEPUDA. One person described how he no longer faced ridicule because of his disability:

All the ridicule I faced because of my disability has turned to praise, because there's nothing that I can't do for … myself. Even among family and relatives, my opinion and knowledge is highly valued.

The chairperson of the Disability Forum explained the positive effect that the empowerment of people with disabilities had had in the area:

I wish for CREATE to grow and go further and continue with these workshops because they are very helpful to us. They have made us the "untouchables". People with disabilities quickly refer to what is stated in the Constitution, you can't touch them.

Important developments, mentioned by people with disabilities, municipal officials and traditional leaders, were that people with disabilities were representing themselves at all levels in community structures, including war rooms[6] and ward committees, and that the executive of the Disability Forum was meeting regularly with the local municipality. One person with a disability described it thus:

The municipality has recognised us and included us in different structures. Self-representation was something that the municipality has done very well and it has helped and empowered us.

This presence and participation in community structures has benefited traditional authorities and the municipality. For example, as one *induna* explained:

They have platforms where they make their voices heard. For example in war rooms, ward committees … We did not know the problems that people with disabilities have but because of their involvement in the different community structures we become aware of their problems almost every time.

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6 "War rooms" were introduced by the President's office in 2008 to facilitate the reduction of poverty. These war rooms entail visits to the poorest wards by teams that include municipal and government officials, with the intention of identifying the residents' specific needs and accelerating their access to government services. The Sukuma Sakhe war rooms prioritise mostly those falling within the definition of "vulnerable groups", which includes people with disabilities.

According to a person with a disability the municipality had also responded positively to the active participation of people with disabilities in these structures. This person said:

The inclusion of people with disabilities in local structures has helped a lot because once the problem is addressed at the war room or ward committee the municipality will send someone to deal with the problem. It is working for us because we do not have to sit with a problem for many months.

A number of people, including traditional leaders, talked about changes in the way traditional authorities now viewed and dealt with people with disabilities in KwaSokhulu Traditional Authority. Traditional leaders were described as taking an active role in the inclusion of people with disabilities in their communities. They were reported to be speaking about disability in their meetings, hearing cases involving people with disabilities in their traditional court and acting on the need for accessible buildings and services for people with disabilities.

We [traditional leaders] always encourage inclusion of people with disabilities in community projects. For example in the RDP [Reconstruction and Development Programme] houses projects we negotiate with the relevant people to build the houses of people with disabilities in a place that is accessible and not too far from the road.

People with disabilities in KwaSokhulu have a good relationship with the chief; he granted land to the Zisize Disabled People's Organisation (which is the basis of the Disability Forum) and gave permission for the formation of the Disability Forum. There is even a person with a disability in the *Umkhandlu* (traditional council), which is unheard of in other areas. The chairperson of the Disability Forum is full of praise for the chief:

But I definitely commend our chief. Even though he is old, he has learnt to work with something he never expected he would. In the past, it was a superstitious belief that if there was a person with a disability at home, then there was something wrong, or someone in the family had done wrong. You had to go to the sangomas [traditional healers] and find out what was wrong. The birth of a person with a disability was considered bad luck. The chief is very old, about 100 years or so, but he has done better than other younger chiefs, who still don't know that people with disabilities are people too, who also deserve services given to other community members.

A number of people with disabilities expressed enthusiasm and delight at the way they were being treated by traditional leaders. One person said:

Inkosi has been very supportive. The fact that … [a person with a disability] sits on the traditional council, it feels like we have won the soccer World Cup.

And another person added:

The good thing is that traditional leaders are talking about people with disabilities in their meetings, which has improved the situation of being discriminated against on the basis of disability.

The attitudes and actions of the traditional leaders do not only benefit people with disabilities in the area. It has also had an impact on community members in general.

The fact that the inkosi gave us a piece of land, the members of the community had no other solution but to respect people with disabilities because who are they to challenge him.
– *Person with a disability*

Sometimes you find when there is a community meeting a community member will ask if there are people representing the disability sector.
– Traditional leader

The uMfolozi Local Municipality was praised by people with disabilities for the various services it had provided and the positive attitude it had shown towards people with disabilities:

… the municipality has committed itself to helping out with transportation, even though they don't have enough fleet. They transport people with disabilities from their homes to SASSA offices, or Home Affairs, or hospital, should they need to see a doctor. This was very surprising to us because not a lot of municipalities do this. Actually, it has never been done. So the Mbonambi [uMfolozi] municipality definitely plays a big role in that way.
– Chairperson of the Disability Forum

The municipality has put people with disabilities on the map …
The municipality has put effort into improving the situation of people with disabilities by putting disability in the IDP, self-representation of people with disabilities, budget for people with disabilities and one official that will process the needs of people with disabilities.
– Parent of a child with a disability

In spite of the progress and positive ways in which disability is dealt with by the traditional authority and the municipality, there are still a number of challenges experienced by people with disabilities who live in uMfolozi Local Municipality. One of the key issues is the difficulty in communication that traditional leaders and municipal officials have with people who are deaf and those with speech and language impairments. There is no sign language interpreter in the municipality and leaders and officials find it difficult to understand people with speech impairments. As yet, there is no Braille

3.3.1 Services provided by uMfolozi Local Municipality to people with disabilities

Services Provided

- **Transport** to hospital, SASSA and the Department of Home Affairs with a vehicle adapted so that it is suitable for people in wheelchairs

- **Paying rent** for an office for the Disability Forum

- Conducting and supporting **disability awareness programmes** in the community

- A **sizeable budget** (R250 000) for disability services in the municipality

- Funding for **sign language training** for four people

- Providing **internships** in the municipality's departments for people with disabilities

- Disability is included in the municipality's **Integrated Development Plan** (IDP)

- Paying for two people with disabilities to undertake the necessary training and examinations to obtain their **driver's licences**, and paying the fees for one person with a disability to become a **social worker**

copy of the IDP available for blind people in uMfolozi Local Municipality and some public buildings are still inaccessible (although this does not apply to the municipal offices or the traditional court). Some people with disabilities who participated in the research for case study indicated that they still

experience discrimination from their families and from minibus taxi drivers. There was also a feeling that within the disability sector itself there had been some discrimination – based on impairment type and sometimes related to age.

When I was elected as leader of our Disability Forum, they said they didn't want to be led by the blind. This was said by people who had disabilities of their own: using wheelchairs, crutches …

What is hindering youth and children is that the executive committee of people with disabilities do not address the interests of youth and children. It is good that they organise school and assistive devices for them but they do not give them an opportunity to talk about the challenges that they have in the community. – *Traditional leader*

3.4 Timeline of changes regarding disability

In spite of the challenges detailed above, there was general consensus from municipal officials, traditional leaders and people with disabilities that there had been a significant change in the situation of people with disabilities in uMfolozi Local Municipality and KwaSokhulu Traditional Authority over the last few years.

The situation is definitely a whole lot better than what it was five years ago. I remember back then, you couldn't even get inside the municipality … It's sad to think about those times. But those who served both the previous and the current term have definitely learned a lot on how to treat us. They now welcome us with open hands; they even try to assist us financially with our meetings and projects. – *Deputy Chairperson of the Disability Forum*

The councillors who served in the previous term couldn't think of anything that a person with a disability would want from the municipality. We were a nuisance to them; whenever they saw us coming in, they wouldn't welcome us in any way. – *Person with a disability*

It's unlike before. Different structures in the community talk about the inclusion of people with disabilities in all community structures, which is something we had never seen before. – *Parent of a child with a disability*

There's definitely a change. Their cases are now being attended to [at the traditional court]. Back then nobody even wanted to take them [people with disabilities] to the *induna*. They were kept indoors. – *Municipal official*

It is no longer people with disabilities only that speak about disability issues but as traditional leaders we have started to talk about people with disabilities and the needs that they have in the community. – *Traditional leader*

3.5 Reasons for changes in uMfolozi and KwaSokhulu

The participants in the case study identified a number of reasons that they believed had resulted in changes for people with disabilities over time. There seem to be many intertwining factors which combined to produce the positive conditions for people with disabilities that were unlike those CREATE has seen anywhere else.

3.5.1 A strong leader who does not stop working

All the stakeholders involved in the study – people with disabilities, traditional leaders and municipal officials – were in agreement that one of the most important reasons for the positive developments for people with disabilities was the presence and actions of the chairperson of the Disability Forum. Mr A[7] is described as being hard-working, persistent and respectful of traditional leadership. Long before any support was forthcoming from traditional leaders or the municipality, Mr A persistently made efforts to start a disability group in the area. He described what he had experienced:

I remember going before the chief to talk about establishing a group and getting people with disabilities together to talk about things relating to disability. He sent me away, said I was talking nonsense … But I wasn't discouraged. I held meetings under trees; we would meet on our way to the clinic and talk [with people with disabilities]… After a while I went back to the chief. This time he welcomed me.

7 "Mr A" is used as a pseudonym to honour an undertaking to avoid identifying case study participants.

Since the formation of the Disability Forum, Mr A has not stopped his work of mobilising people with disabilities in the uMfolozi Local Municipality.

Mr A is amazing. He mobilises people with disabilities in the wards, it is amazing. It makes it easier to know the situation of people with disabilities in their homes and wards. – Traditional leader

Mr A seems to relate sensitively to the traditional leaders in KwaSokhulu and has managed to garner their support, historically this is a very difficult constituency for people with disabilities to work with.

Although he is a member of a certain political party but he respects me as his induna. He is an asset in my ward. He is politically minded and can mobilise community members especially people with disabilities. You might think he is arrogant and disrespectful but he does respect me as his induna … I think his skills show that wherever he is, he makes sure that he talks about disability. I think that is why the members of the community did not have a problem to vote for him to sit on the traditional council. He is strong and has community interest at heart. I was so impressed the other day when he was talking to the local radio station and he explained his role in KwaSokhulu Traditional Court. He explained that he is well treated by his inkosi and izinduna. I was so proud of him. – Traditional leader

Mr A is also seen as an asset to the uMfolozi Local Municipality and not only to the Traditional Authority. At times he will accompany a person with a disability when the municipality transports the person to SASSA to re-instate a disability grant. He and the Disability Forum executive are the links between people with disabilities in the community and the municipality. He communicates with and motivates people with disabilities throughout the municipal area. He is respected by his own constituency as a hard worker.

Mr A is so dedicated, you cannot say he is not getting any salary [he is not employed on a salary]. He is not selfish. Whenever he comes back with information, he shares it with us and the leaders. That is keeping us on our toes because we know that once he gave the feedback, we must implement it. – Person with a disability

3.5.2 Empowered people with disabilities who are organised and represent themselves

Although Mr A has been the primary mover of the disability sector in uMfolozi Local Municipality, many members of the Disability Forum are now empowered to represent people with disabilities in different community structures. Not only is self-representation important to people with disabilities themselves, it is also important for traditional leaders, community members and municipal officials because it allows them to see that people with disabilities can stand up for themselves and be contributing members of society. The municipality encourages self-representation, as explained by one municipal official:

We don't want anyone without a disability to represent them, like their slogan says. We only want a person with a disability. They must seek them out in the communities. Every ward must be represented. When we talk about central plans, we talk to someone who comes from the disability camp.

People with disabilities and parents of children with disabilities who participated in the focus group discussions explained the different aspects and contributing factors to their empowerment and self-representation:

Firstly they have recognised us as the existing and organised sector.

There is so much difference now. People with disabilities have rights that are protected by our Constitution and we have CRPD and PEPUDA. Even if we face challenges in the community … we know that there are laws that protect us.

We can't keep quiet about our rights. We fight to be accommodated like everyone else, and receive services that everybody receives. We don't want there to be any exclusions. That's why we don't want anyone to talk on our behalf, without involving us.

But after we showed them that we do in fact know about our rights, there was a definite change in their mindset. In this municipality in the past, you wouldn't find a person with a disability in any of the committees here. But now you do find that there's at least one representative for people with disabilities among the 10 ward committee members in every ward.

They [people with disabilities] are able to do a lot on their own, even without the leadership of the group. They no longer need people to accompany them, they can speak for themselves. That's the change I can say has taken place at the uMfolozi Municipality.

3.5.3 Traditional leaders who have taken disability issues on board

In earlier research conducted by CREATE in the KwaSokhulu Traditional Authority, a number of people with disabilities complained of being denied justice in the traditional courts. They also complained that they were not treated equally by their traditional leaders and that the court was not accessible. At the time, the traditional leaders described themselves as being scared of people with disabilities and offended by a person with a disability who spoke out. This case study has revealed a marked change in the attitudes and actions of the traditional leaders. Traditional leaders still play an influential role in rural society in KwaZulu-Natal, so these changes on their part can have an important and beneficial impact on the communities they preside over and the people with disabilities who live in them.

During the case study process, one *induna* provided an example of how a person with a disability accessed justice through his [the *induna*'s] actions and those of various community members – such an occurrence was previously unheard of.

In my area two guys robbed a person and they thought that because of his disability he would not be able to identify them. The members of the community worked together with me as *induna* to find the guys … Imagine the time when we did not have enough information about people with disabilities we were going to wait for the social workers to help, but we did it

ourselves as the members of the community and justice was done. We were very happy.

The traditional leaders now also consider accessibility of their buildings and of houses and other services for people with disabilities. This then provides a positive example for community members as well as benefiting people with disabilities.

In our traditional court we also have an accessible toilet which is good. I think this is good because when people with disabilities have meetings at the traditional courts they do not have problems because the toilets and the court hall are accessible. – *Traditional leader*

As alluded to previously, the traditional leaders also talk openly and with more knowledge and information about disability in their own meetings and in community meetings.

3.5.4 The importance of being educated and informed

CREATE has provided training to people with disabilities and parents of children with disabilities from uMfolozi and uThungulu District Municipality and to traditional leaders from KwaSokhulu Traditional Authority. Many participants in the case study mentioned how important it had been for them to learn about disability and disability rights and how this training had been instrumental in achieving the improvements in the situation of people with disabilities in uMfolozi Local Municipality.

After the training we saw that as much as Mr A is promoting the inclusion of people with disabilities … we also have the role to play. – *Traditional leader*

… the knowledge we have gained as people with disabilities is what has helped to bring change. A person with a disability can request services they are entitled to because they know their rights.
– *Chairperson of the Disability Forum*

I think had we had these trainings a long time ago, many of our people would not have been abused and neglected by the traditional courts. Trainings are very important and the information they give is very important. We would like for these trainings to continue and spread to other chiefs and traditional leaders, so others like us don't suffer while we are free and enjoying ourselves.
– *Deputy Chairperson of the Disability Forum*

Before the CREATE training we knew there were things called "law", "policies", "Bill of Rights", "Constitution" and so on, but we thought that it is something that you get from Pretoria or Cape Town and it is for lawyers or educated people only. We now have information and we use it to challenge government departments. – *Person with a disability*

Another aspect of the training that was identified as being particularly important was the fact that the manuals were written in *isiZulu* and were therefore accessible to those *isiZulu*-speaking people who were not literate in English. The training and the manuals were culturally sensitive which also seems to have assisted.

For the real liberation started when CREATE, Office of the Premier and LRC trained us. I am saying this because the training was in *isiZulu* and the material was in *isiZulu*. – *Person with a disability*

It has to be ibhukwana [manual], you can even use it when the teacher is not around. It explains everything very clearly. – *Traditional leader*

We also share the information in the manual a lot ... it is like our Bible because we refer to it now and then. – Traditional leader

3.5.5 A municipality that responds to the persistence of people with disabilities

In the focus group discussions, interviews and the PRA session, a number of parents and people with disabilities told of the responsiveness of the municipality to their advocacy efforts.

Because of the strong leadership that we have, we were able to talk with the municipality and request that a number of people with disabilities be considered for the EPWP Project. Even though it's temporary employment, we also want to benefit from it. They asked some of us to submit our CVs. – Person with a disability

Several people with disabilities spoke about the changes that had happened within the current term of councillors and the Mayor – they reported being able to speak to municipal officials directly, they said they felt welcomed, that there had been an effort at making buildings accessible and that the municipality had directly supported Zisize Disabled People's Organisation (which is the basis of the Disability Forum).

As noted previously, the uMfolozi Local Municipality provides resources and undertakes many different activities to support people with disabilities. We also noted, however, that some municipal officials have not fully taken on board the social model of disability, and therefore, in addition to doing such things as raising awareness of disability, the municipality also hands out food parcels, which can be interpreted as more of a charity-oriented approach to disability. CREATE has not provided training on disability and

disability rights for municipal officials at uMfolozi Local Municipality and it is possible that with training, municipal officials would have a clearer understanding of the social model of disability.

3.6 Concluding thoughts

Through conducting the research for this case study in the uMfolozi Local Municipality and KwaSokhulu Traditional Authority we have been able to document some exciting improvements in the situation of people with disabilities and suggest some reasons for these changes. Traditional leaders, municipal officials, parents of children with disabilities and adults with disabilities have all played a role in uMfolozi.

SECTION 4: EMERGING LESSONS

CREATE conducted the research for this case study in order to try and determine not only what the situation of people with disabilities is in uMfolozi Local Municipality and KwaSokhulu Traditional Authority, but also to try and understand what contributed to that situation. We hoped that by coming to a deeper understanding of what has enabled the positive environment for people with disabilities, other municipalities and traditional authorities might follow suit. Although we have most likely not unearthed all the contributing reasons for the changes at uMfolozi, in this section we share what we feel are the important lessons we have learnt.

Lesson 1: The need for a disability champion

We learnt of the crucial role of Mr A, the chairperson of the Disability Forum, in developing an active group of people with disabilities and then advocating for their inclusion in society. Although the training interventions from CREATE enabled people with disabilities to know their rights, and traditional leaders to understand inclusion, it was Mr A's persistence, diplomacy and advocacy that contributed greatly to changing the attitudes of the traditional leaders and municipal officials. His acceptance by the community and his election to the Traditional Council as a person with a disability both signifies the positive changes towards people with disabilities and also acts

to stimulate further engagement with issues of disability inclusion in the community.

In the case of uMfolozi Local Municipality, Mr A was already a disability activist before any intervention from CREATE or other external organisations. We did not deliberately seek out a disability champion before working in the area and yet his presence and participation seem to have made a significant impact on the implementation and follow through of what has been taught and learnt. Perhaps the lesson to be learnt from this is that wherever work to promote respect for the rights of people with disabilities is taking place, in order to truly garner support for a disability-inclusive society a disability activist or champion should be sought out,

nurtured and supported. It is so important for people with disabilities to speak for themselves and having a local disability advocate strengthens the impact of any interventions that may be made.

Lesson 2: Self-representation of people with disabilities

Self-representation is something that CREATE both advocates and practices; it was gratifying to see the impact of this once it was taken on board by uMfolozi Local Municipality and the KwaSokhulu Traditional Authority. We are not aware of any other municipalities being so rigorous about making sure that people with disabilities represent themselves in all their war rooms and ward committees. This presence in community structures makes disability visible and something that no longer needs to be feared or stigmatised by community members. Self-representation on community structures helps people in these structures to move away from a charity approach to disability, to being able to see that it is a matter of rights and inclusion. At the same time, the representatives with disabilities build up their own skills and self-confidence while other community members with disabilities and parents of children with disabilities have people who provide a voice for their concerns.

We strongly recommend that municipalities and traditional councils consider how people with disabilities can be included in community structures to represent their own interests and speak for themselves. Through promoting self-representation, municipalities and traditional councils will increase their knowledge and they will be acting in the spirit of the CRPD, which guides all policies and laws in South Africa concerning disability.

Although many people with disabilities may have experienced discrimination and be lacking in self-confidence because of such experiences, with training and the formation of DPOs, such as Zisize DPO in uMfolozi, disability activists and self-advocates can be developed and can learn appropriate skills. How much more inclusive and welcoming our communities will be if we have people with disabilities representing themselves at all levels of community structures.

Lesson 3: Linguistically and culturally appropriate training

This case study has highlighted the importance of tailoring any training to the culture and language needs of the people being trained. People with disabilities, parents and traditional leaders all expressed their appreciation of the training being conducted in *isiZulu* with culturally appropriate characters and uncomplicated language in the manual, suitable for those with low levels of literacy. If sustainability and implementation of the training is to be achieved, participants need to have an accessible manual which can be referred to after the trainers have left.

We have also learnt that it is crucial that the trainer understands and deeply respects the culture of the people she is training. This is especially important when working with traditional leaders who are particularly concerned about protocol being observed. Although it can be argued that traditional leaders in KwaZulu-Natal are not known for their adherence to and respect of the rights of women, children and people with disabilities, this case study has shown that with culturally sensitive training, a flexible and respectful trainer and a disability champion, traditional leaders can incorporate respect for the rights of people with disabilities into their culture and governance practices.

Lesson 4: Working with people with communication impairments is difficult

Of all the different types of impairments, traditional leaders expressed having the most difficulty in working with people who have communication impairments. It is relatively easy to put in a ramp or an accessible toilet, but communicating with a person who cannot read while you cannot use sign language is challenging. The uMfolozi Local Municipality together with the uThungulu District Municipality is trying to address this problem by sending people for training in South African Sign Language. Unfortunately learning

sign language will not solve the problem of communicating with people who have speech impairments as that requires patience and experience in listening to people who are unable to speak clearly. People with speech impairments appear to be the most marginalised group of people with disabilities in uMfolozi. This observation was supported by the people with speech impairments who participated in the research.

The lesson to be learnt is that any training should deal with all impairments and not just with the more common and visible impairments. Traditional leaders, municipal officials and people with disabilities that are not related to speech impairments need to learn strategies for communication with those who do have communication impairments and who, because of those impairments, find it most difficult to represent themselves.

Lesson 5: The struggle for disability rights and disability inclusion takes time

Despite the progress that has taken place in uMfolozi Local Municipality and KwaSokhulu Traditional Authority, as one person with a disability pointed out, "The situation is not 100 percent perfect but there is a lot of difference." There are still various leaders and officials whose attitudes have not changed markedly. Mr A showed the value of patience and persistence in getting permission from the chief to set up the Disability Forum. These same attitudes are required to help a community move towards the inclusion of people with disabilities and to respect the rights of these people.

CREATE was first involved in training some people with disabilities from uMfolozi Local Municipality in 2011. Even when the research into access to justice for people with disabilities in the traditional courts in uThungulu was undertaken at the beginning of 2013, there were still numerous reports

of discrimination against people with disabilities in KwaSokhulu and Ntambanana. As has been shown in this case study, progress is certainly being made, but there is no "overnight fix" available to change attitudes and behaviour towards people with disabilities.

SECTION 5: CONCLUSION

This case study illustrates what is possible and how a situation can change from one of stigma, discrimination and marginalisation of people with disabilities to their acceptance into mainstream society. Those who have worked with rural local municipalities and traditional leaders are particularly well placed to recognise the seismic shift that has taken place in the attitudes and actions of the traditional leaders and municipal officials in KwaSokhulu and uMfolozi that are described in this study. When leaders and public officials such as these accept people with disabilities and show respect for their rights, then community members follow and disability inclusion starts to become a reality.

A strong, hard-working and persistent leader with empowered members of the Disability Forum has made self-representation a powerful tool to make disability visible and respected in the community in uMfolozi Local Municipality. Training provided by CREATE assisted these advocates by providing them with knowledge of their rights while at the same time the training of traditional leaders appears to have made them more open and willing to listen to and include people with disabilities in their communities. The municipality has taken on board the South African laws and policies as well as the CRPD, which guide disability inclusion, and here too self-representation of people with disabilities has been very important. The struggle for respect for the rights of people with disabilities in uMfolozi and

KwaSokhulu is not over, but there has been a giant leap forward; all parties need to continue on this path.

What does this say for other municipalities and traditional authorities? People with disabilities, supported with information and training, should be sought out to help lead the way to disability inclusion. Their involvement in community structures accompanied by culturally and linguistically-appropriate training for traditional leaders and municipal officials can make a big difference in the lives of all people with disabilities in rural communities.

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