

chapter 10

fadila the

activist

Interview with Fadila Lagadien



Fadila Lagadien, quadriplegic 'senior statesperson' of the South African disability rights movement, running an Employment Equity workshop for a major South African corporate. Fadila has represented the movement on many levels, most recently as Convenor of the Community Constituency in the National Economic Development and Labour Council (NEDLAC) and now on the Board of the South African Broadcasting Corporation. Fadila has her own consulting company, 'Closing the Gap', focusing on the area of disability employment equity.

Taking her lessons from the struggle years in South Africa, Fadila Lagadien has carried her activism into the boardrooms and negotiating chambers of our new democracy. However, she has some disturbing things to say about how things are today.

Fadila, you came into the disability rights movement by accident, and I mean that quite literally. Would you share with us that traumatic experience?

I was in a motorcar accident, a head-on collision. I was the only female and the only black person, with three white males, one of whom was my boyfriend John. The driver died on the scene, I broke my neck, and the other two had lesser injuries, like broken legs, dislocations, and that sort of thing.

That was in 1986, and you know how it was in those apartheid years; to be found with a white guy was a terrible thing. He went to a white hospital and I had to go to a black hospital.

We were on our way to Sun City from Johannesburg. John was a telephone systems engineer at the casino there. The ambulance took us to the nearest hospital, in Rustenburg, but they wouldn't take me. They put a soft collar on my neck – bearing in mind that it was broken at the level of c4 – put me on a stretcher and left me in the passage, while they took John to the theatre to put pins in his broken leg.

This happened Saturday evening round about 9 o'clock. They drove me by ambulance to HF Verwoerd Hospital in Pretoria the following day, and I was lying in the passage on the stretcher all that time. I got to HF Verwoerd on Sunday afternoon round about visiting time.

That's where it really all started, because when I realized that the conditions where I was were very different from the conditions where John was ... that's when I started making a noise through the newspapers and through my lawyer. You were one of the first people that came to visit me – a stranger out of the blue – having read these things in the newspaper. I didn't know at the time who you guys were, but when I got out of hospital and got my life started again, I began looking for other disabled people and a movement of sorts. I then realized that the people that came to see me were from the disability rights movement.

Author's Note: Fadila and I have different memories of our first meeting, perhaps complementary ones. DPSA, together with Lawyers for Human Rights, had just launched a new project called Discrimination Watch and as Chairperson I was the active agent. On learning that Fadila was being denied intensive care at the HF Verwoerd Hospital, where it was freely available to white patients, I decided to make an intervention, but we needed Fadila's consent to act on her behalf. Intensive care was extended to Fadila following a ruse to

create the impression with the hospital superintendent that the State President was displeased with the set-up.

| Your homecoming must have been difficult. Would you tell us about that?

When I got out of hospital, I tried to resume my normal life as soon as possible, but wherever I went there were just major obstacles. First of all it was the structural barriers; I couldn't get into places – I couldn't get into my own flat, can you believe it? So that was my first rude awakening, with 'Wow! What's going to happen here?'

That was on weekends when I went home ... This big schlep up the stairs. John then found another flat and that was our first introduction to accessibility. And then I tried to do normal things, like shopping or going to the movies, and 90 percent of the places I just couldn't get into.

Then there were the attitudinal barriers. That started right in my family. Suddenly they treated me differently; I think they thought I couldn't think for myself and make decisions any longer. An example would be my sister then coming to stay with us. She would never ask me 'what shall I cook?' She would just cook and give me to eat. She would never even say, 'do you want to come and cook with me today?' I was just there.

| And you're a good cook, aren't you?

Oh, I am an absolutely wonderful cook ... Then I overheard my sister speaking to my aunt and saying: 'You know, it's just easier if I do it and don't involve her.' And I thought, 'my God! Am I now so much of a burden?' And I would say to John, 'let me come and sit in the kitchen while you are preparing the meal.' And he would say, 'No, it's okay, just sit on the couch.'

Do you want tea? Do you want this, do you want that?’ And they would just fetch and carry and it drove me nuts. I felt totally and utterly useless in every which way.

So what did you do?

I thought, no, this can’t keep going on. And then I heard about someone called Kathy Jagoe doing something called ‘disability awareness’. Although that was not what I wanted to do, I just knew that I wanted to tell people that I had not changed. So I scouted around and, obviously, I had your name somewhere because you had visited me in hospital, but as usual you were out of the country at the time. But I did get hold of Kathy and she told me about People for Awareness on Disability Issues (PADI), the organization she started, and she told me about Mike du Toit – so you were the first three in my reference of a movement in South Africa.

Then I tried to get hold of Mike – this was all over the December period – and he was away fishing. He was just on holiday – and it seemed like a perpetual holiday. But when I eventually got hold of Mike, he said that you are the Chairperson of the movement and that I should be speaking to you, and he told me a bit about what DPSA does.

Kathy had moved to Cape Town and I was still in Johannesburg. I traced her and she came to my place and we met. My place was so inaccessible that we sat out in the driveway, because she couldn’t come into the house. And she said: ‘Why don’t you start in Cape Town – People for Awareness on Disability Issues? There’s one in Jo’burg and I left it. I don’t have time because I am setting up the disability unit at Cape Town University.’

This was like a major task. She said: ‘Fadila, you know I’m going to support you.’ Which she did; she gave me all the

materials and she put me in touch with Sandy Heyman, who was running the one in Jo'burg. We quickly got an organization started. And PADI then grew, and grew, and grew. At that point there was very little other than Vukuhambe Self-help happening in Cape Town, and the Access Committee. PADI was the most regular, most visible thing in terms of disability.

What were the activities of PADI?

Newspaper interviews, radio interviews, and media articles; I did many articles in many magazines. I just kept trying to get the message out about disability.

I started really by talking about myself, telling my story. Then I began putting out articles calling for disabled people to join me in doing this awareness thing, and the response was phenomenal. It was unbelievable, the amount of people that came forward. So we had a group and next we went through some weekend training. I couldn't believe that there were so many disabled people out there, just sitting in their homes, stuck away.

After our training we started getting bookings for workshops, from schools, churches, universities, hospitals. And when I heard more about DPSA I did a similar thing, calling for people, and I started forming DPSA Western Cape.

The logical progression was to have some sort of publication. Because of what we found in our workshops, we just felt that we needed to do that. The magazine was called disABILITY – not such a negative name because of the way in which the word was written – the dis was small and the ABILITY was big. And I did lots of fundraising for PADI and DPSA. I was Jack, Paul, Arthur, Martha – all rolled into one. That's just who I am; I am very much the pioneering type. I cannot stay

too long in one thing. I set things up and when they are good and solid, I move on and set up the next thing.

Coming now to DPSA: do you have any memories from those early congresses?

Oh yes, plenty! That has got to come back ... I hate the way DPSA has restructured these conferences. I mean, it was a lot of fun. At the time we were aligned with the liberation movement that was happening in the country; so it was vibrant, very vibrant, in the things that we did, the campaigns that we put up, and the types of people we spoke to. It was just a different kind of movement then.

I think we are partly to blame: we believe that now, because we are a democracy, things are suddenly hunky dory – and they are not. We don't engage in protest action any longer, and I think that should still happen. That's what we did in the early congresses ... That's what made them vibrant. That's what made us achieve the things that we did – such as the disability white paper, such as getting ourselves into all the policies.

I think you know, William, what happened then was a natural progression. From there we went to the elections. Remember how we were a bit confused, whether we should become a political party or stay a movement? Those are the kinds of things we discussed at the congresses. I mean, it was real, real stuff. It was meaty stuff. Now it's kind of cake and tea.

From there the natural progression again was to become involved in writing the legislation of the country, as it stands today. And I've been involved extensively in just about every single piece of legislation, through our activism.

A particular contribution of yours was in the writing of the Code of Good Practice under the Employment Equity Act ...

That was my most recent task. Previously I was involved in many other pieces of legislation, including the Employment Equity Act which gives the Minister of Labour the right to call for a Code. DPSA formed a consortium and won the tender, and I was part of the multidisciplinary group that wrote the Code. There were six of us and we divided ourselves up into teams of two and each would take specific sections. I wrote the parts on recruitment and selection, placement, and reasonable accommodation.

Through no fault of our own, it took about two years to complete the Code. It went through many stages, and phases, and processes with the government and the Commission on Employment Equity. It is kind of launched in a draft form, and now we are writing the technical assistance guidelines.

Fadila, I wonder whether you can remember an incident in East London many years ago. We were sitting in a Combi along the beachfront somewhere and you were talking about the days of apartheid. And then you said something that still haunts me today; you said: 'When I was young and beautiful, I couldn't go on this beach; and now that I am allowed, I can't because of my disability.'

I know exactly where we were ... We were there for a DICAG conference – the Disabled Children's Action Group – and we were at Orient Beach, near the restaurant there. And as I looked out of the window and over the sea, I remembered with such, such nostalgia that this is where I was born and brought up. And never in those 27 years was I allowed to walk on that beach, let alone sit in the restaurant. I worked on the waterfront in various hotels and restaurants and I was

only allowed to go on the sidewalk – not on the beach, not on the sand. And now that I can go there, I can't get to the water and the sand with my wheelchair.

That still keeps me away from East London ... That's the ghost I have to deal with. There's nothing in East London for me; I have no lost love for the place. But it doesn't take away from the beauty of the city, the tranquility. I probably will go and retire there some day ... but not yet.

Would you tell us a little bit more about those early years, before you became disabled?

I had to leave school before I even finished standard six (I must have been about fifteen years old), because there was no money for school. We were quite poor and my dad took ill. I was the eldest in the house, and I had to go and step out and work. And I thought, okay, I'll do work and study.

And my first job ... you know I will never forget this: I went the Monday morning and I said a little prayer; and I said, 'God, you know I have to work, but if I don't get a job on this first day, then I know I am not meant to work, then I will go back to school.'

The first place I walk in, I get a job. But did I cry! I just cried for joy for getting a job, and I cried because I can't break the promise that I just made.

So my first job was in a Wimpy Bar inside OK Bazaars (Wimpy's were not yet stand alones as they are today). From there I moved to the OK store itself, that's where I went. I tried doing evening studies, but it's a full day and there's no energy left for anything else – and I dropped out.

And through the years I just worked at this job and that, but I stole a lot with my eyes. I let people make a lackey out of me

– do this, do that. I never said no, because every time I did something I learned something. And those were really my schooling years, until now, at the age of 42, I started formal studies doing an MBA with Liverpool University, just through them doing an assessment of prior learning.

You represent us on NEDLAC (the National Economic Development and Labour Council), don't you? What sort of work do you do there?

I've always represented DPSA at some level or another and this was just a natural progression from being in all the local stuff. NEDLAC was instated by Government to promote social dialogue between Government, business, labour, and civil society. At the beginning NEDLAC was just filled with men, half of whom were white, but the way the country was going, with equity and diversity, they decided to restructure themselves to get gender balance, racial balance, and disability, and I then came in, about five or six years ago.

Any policy or piece of legislation, before it goes to parliament, it comes to NEDLAC. We negotiate the contents between the parties – the Water Bill, the Housing Bill, whatever – every piece of legislation passes through NEDLAC. That gives us a wonderful opportunity to be involved, because the disability movement has equal status on NEDLAC. That's one of the big reasons we don't have a Disability Act; we are covered in every single piece of legislation, if not explicitly, then implicitly, because of our Constitution that outlaws discrimination on the basis of disability.

I have grown tremendously and learned an extreme amount. I've really been thrown in at the deep end. I don't know if you are aware, but I have just been nominated to be the overall convenor of the Community Constituency. So I'm right up there with the big guys!

Congratulations, that's a great achievement! But now I want to turn to matters personal and your business activities.

I'm sick and tired of fundraising and saying please give me, please give me, and just making it and just surviving. Now you know my involvement in all these pieces of legislation and policy writing ... When we were busy with the affirmative action green paper I saw a business opportunity. I realized that diversity is here to stay, and employment equity in particular. But there's a gap: people have never had to employ disabled persons and they do not know how. And so I developed a model for the training and placement of disabled people in the open labour market. This model is not going to go into the NGO sector, but into the business world, because the potential to make money is huge.

And then I registered my company, Closing The Gap (CTG), because that's exactly what I want to do, to close the gap between disabled and non-disabled people. This is one of the reasons I am doing an MBA; being a woman, being black, being disabled, people in the business world don't take you seriously, especially if you don't have a piece of paper to show you have a qualification. Even if I could demonstrate proficiency, it means nothing. The MBA for me, in all honesty, is a walk in the park – there's nothing that I haven't done before.

The one thing that was a bit difficult was quantitative statistical analysis, because I have never done maths – I told you I left school in standard six. It was total gibberish, but I got a C and it's just the most wonderful grade. I feel like it's an A plus plus. So the reason I am doing this is to legitimize myself in the business world.

Who are your corporate clients?

I have many corporate clients. I started with Sanlam, which is the second largest insurance company in South Africa. Metropolitan was another, and I have done work for Santam – all insurance companies. I think the reason is that the insurance industry is the most ready to employ disabled people. And then I worked with Caltex and Shell, and several others; it's still growing.

What service do they want from you?

Consultancy. Because of the Employment Equity Act everybody is obliged to develop an employment equity plan. They need to audit their workplaces ... see where the equity gaps are; where do they need women, disabled people, black people? It's like taking a snap shot of where the organization is and then developing a plan for them to get where they want to be. Coupled to this is writing workplace policies on disability, reasonable accommodation, HIV/AIDS. We do pre-employment assessment and post-employment support.

So you helped to write the legislation and now you make people pay for your advice.

Yes, now I am making money out of it. Can you get any cleverer than that? Although I must say there is not a huge willingness to pay for the service. I make the analogy that if I knock at your door and want to come into your house, you certainly are not going to pay me to come in, because you don't particularly want me there. But people are obligated through legislation – so I push that part a bit. So I play a dual role: I am still an activist and I could report them, but I am also a professional consultant with my persuasive abilities.

My MBA dissertation is going to be to build a business case for the employment of disabled people. It's not about charity, it's not about social responsibility, it's not about doing us a favour. It's showing businesses you can make more money if you employ disabled people. I don't want them to see it as their social responsibility, because then we never gonna advance. We might enter into the workplace, but we will never advance.

Fadila, we've come a long way in the disability rights movement over the past twenty years. What for you have been the main achievements?

The biggest achievement was getting ourselves located in the President's Office. However, we still have to make that work for us. It's not working for us the way we intended it to. Having said that, the next biggest achievement for me would be that we have gotten ourselves as disabled people written into the Constitution of the country. I think we have one of the most progressive constitutions in the world and we are protected by the highest law of the country, but we haven't yet begun to test the Constitution, or the Equality Act that we have, to take anything to court.

And what are your feelings about the state of the disability movement today?

I think it's run out of steam. The gender movement went the same way. We had the opportunity to put disabled people into parliament and highly placed positions and a lot of our leadership went there, leaving the movement quite weak. Another reason is that personalities in the movement are not leading us the way we intended. There's a red thread that has to run through everything. We didn't haphazardly do these things; we had a plan, we had vision. And somehow the continuity hasn't been picked up by the new personalities.

It's a sad, sad day ... Somebody in the movement said to me one day when I was tendering for something, I need to understand that I must separate my activism from my professionalism. I don't think I can do that. If that's the kind of thinking we have in the movement today, then we are desperately in need of change.

Then it is also the fundraising situation. Funding was easily available. We could go and do fundraising outside the country – it would come into our pockets – but now with bilaterals, government to government, all that has changed. And the instruments that we put there such as the Office on the Status of Disabled Persons, The Federal Council, The Thabo Mbeki Development Trust, all of these things, they're not working for us the way we intended for them to work.

Now whose fault is it? I think we are partially to blame. A lot of us just got tired, because you give so much of yourself, and then in the last three or four years things have just stagnated as new and other leaders came in. My own steam is bietjie uitgerun ['has run out a bit'], but I can't separate myself from it. How do you put yourself to bed and say to yourself 'you just gonna stay there'?

| To end with, please give us a glimpse into your family life.

My daughter Sholeen had just turned four when I had my accident. The last pictures we have of me walking are of her birthday party, and we've treasured those always. She has been such an inspiration to me through all this time that I've been disabled. She constantly tells me that she would have me no other way. My biggest fear on coming out of hospital was that my daughter was gonna reject me, and I couldn't have been more wrong. It's the thing that made me fight to survive.

A lot of the schools I got into with my awareness work were through her. She absolutely couldn't take it how kids teased each other: 'You blindemol, you spaz,'

And that kind of thing. She said: 'Mommy, I can't take this; come and talk to my classmates and tell them they mustn't speak like that about disabled people, or to each other.' So at every school that she's been to, in every standard, I've given a talk. I've told my story. And it's a wonderful story. And it's not finished yet.

chapter 11

a voice in the

presidency

Interview with Sebenzile Matsebula



Sebenzile Matsebula, Director of the Office on the Status of Disabled Persons in the South African Presidency, representing South Africa in the United Nations' process of drafting an International Convention on Disability.

The nexus between the new political establishment in South Africa and the disability rights movement is a powerful force for change. The chief agent of change is a single-minded woman, Sebenzile Matsebula, Director of the Office on the Status of Disabled Persons at the Union Buildings in Pretoria, seat of the South African government. This chapter is based on an interview I conducted with Ms Matsebula during the first part of 2004.

What is the purpose of the OSDP and how did it come about?

Both from the point of view of civil society and from that of government – but much more so from that of civil society – there was a recognized need for a coherent unit in the highest office in the country, a unit that would develop programmes to promote disability issues and facilitate the mainstreaming of disability in South Africa. During the reconstruction and development phase immediately after the democratic election in 1994 disabled people were deployed from the movement to work in the new Presidency. Those were the individuals who were responsible for setting up the unit for co-ordinating and mainstreaming.

The primary objective I would say was to ensure that disabled people were no longer shunted from pillar to post. If you had a particular need as a disabled person or as a parent of a child with a disability in the past you would be told to go to department A. You would go to department A and they would say go to department B, and you would spend the rest of your life shuffling between departments with no resources and no joy in sight. So this office has to ensure that that doesn't happen anymore. But also it has to ensure that departments that have line functions deliver on specific mandates, and deliver effectively.

What is the structure of the office and who are the people who work here?

The Office on the Status of Disabled Persons resides within the policy unit of the Presidency. There are a number of management structures within the Presidency, and one of those is the policy unit. Within the policy unit the office is structured to address policy development, policy implementation, policy monitoring and evaluation.

I am the head of the programme, as Director. Currently I have two posts of deputy director and they have specific portfolios as middle managers. One is a media liaison position and the other is a change management position coordinating our provincial and local government work; but many other responsibilities get delegated due to the human resource constraints that we have. We also have four admin officers within the unit, two of whom are contract-based and donor-funded. Also, there is a senior secretary. To add to this, depending on the projects being implemented, there could be one or two managers under contract. An example was the manager we had for economic empowerment. Another example right now is the communications manager who

is responsible for implementing a public awareness campaign.

| What have been the achievements of the OSDP?

Well, you could write a book about that, but let me pick up some highlights. There are several aspects: At government level one of our key successes has been the training in departments. When our new democracy started, a lot of posts were created to ensure the mainstreaming concept, and people were deployed into government departments to facilitate this mainstreaming. Those people would have had experience in social welfare, as teachers, and whatever, but they did not have experience or an understanding of disability. We then trained those people so that, as they discharged their duties, they had a clear understanding of disability as a concept, as a principle, and as a way of living.

That has been a very successful project because, besides creating awareness and making people do their work effectively, it has enabled us to gain allies in government. Because of their strong understanding of disability, these people have become passionate about their work and go out of their way to promote disability issues. So we now have what we call “focal persons”, but they’re actually allies that serve as our ears and eyes and inform us of what is going on and of any problems. If we need an entry point into a department, we know there is somebody who will work with us meaningfully.

| Where have you achieved your greatest successes?

With the majority of departments, and certainly with the key departments of health, social development, labour, education, trade and industry, communications. All those depart-

ments have been active and have participated. We haven't had as much luck with the Department of Transport, primarily because of their ever-happening restructuring. Whenever we make an attempt to train, they're restructuring and no one comes.

Then, that training has also been done with government departments at provincial level, which is even more significant because that's where delivery happens. And now we've moved on to local government – training for local councillors, primarily councillors with disabilities. Our feeling is, much as persons may have a disability, it doesn't necessarily mean that they will be able to articulate issues as effectively as we'd like them to do. And so we've empowered councillors to articulate the issues effectively.

| Have there been any other achievements?

Our public awareness campaigns. We have had several initiatives – not on a large scale – when we would use particular events, like the World Summit on Sustainable Development, where we organized a photographic and art exhibition that generated a lot of interest with people coming from all over the world and they had the opportunity to interact with artists with disabilities and to purchase their creations. We have also used the International Day of Disabled Persons to put up a huge public awareness campaign. Before the day and on the day we would have radio campaigns, television campaigns, publications, for example. It wasn't as large as we're doing it now because now we have somebody focused on it.

Other achievements have been in terms of policy development. The Integrated National Disability Strategy came out

of this office and that has served as a cornerstone for the promotion of disability rights. An offshoot of that policy has been other policies in various departments and we have guided the development of those policies. We've had major policies that have come out, for example on inclusive education, which was a major breakthrough. We were also involved in the development of legislation, such as the Anti-Discrimination Act and the Employment Equity Act, and we have made inputs in a number of ways.

Another initiative has been capacity-building for civil society formations. Because of our own background as disabled persons in this office, having come from that background, we know that a strong and effective civil society is one of the reasons why in South Africa we've been successful when it comes to issues of disability. Initially we identified what we refer to as marginalized groups of disabled people, which would be groups that maybe reside in rural areas or groups of women with disabilities, and we provided capacity through training but also through grants that enabled them to develop their own programmes. That has really been very useful because, while some of those organizations would probably have died, they have been able to sustain themselves to some extent. How far they go really resides within themselves – how they're managing the future.

We have also had an exchange programme with our partners in Sweden where we had civil society groups from South Africa visit Sweden and vice versa. The objective there was not just to share our experiences, but to establish long-term relations, which is happening in some of the sectors, primarily the deafblind sector, where we still do have a great need to give support.

Some people say the disability rights movement in South Africa is running out of steam. Others say no, it's changing in character. What is your view?

I would agree with the latter position. I think it's changing its character and it's because of where we are now. Certainly, we can't exist as a movement as we did ten or fifteen years ago. Now that the focus is changing towards delivery and implementation, the movement needs to focus on that; to say, okay, the foundation has been laid. Now we need to ensure that what disabled people fought and struggled for bears fruit in the sense that we have tangible things happening. We're no longer into philosophies and those kinds of discussion, but we're into how we're making a meaningful and tangible difference in people's lives.

How did you first become involved with the movement?

I first got involved with the disability movement when I was still working in Swaziland. I remember having many interactions with yourself, Friday Mavuso, Maria Rantho – all those people that came out to Swaziland to create an awareness of this new shift in thinking. We had come from a culture of a welfare state, where disabled people were looked after and cared for by charities, by the good Samaritans. Then there was this move: no, in fact that isn't the right thing. Disabled people have a responsibility to effect changes in their own lives. That was my first exposure, which I must say was a wonderful exposure. I was involved with the sector from 1986 as a researcher – because I was trained in the sciences – but it wasn't until 1988-89 that I got involved with the movement as a movement of people with disabilities. I have been involved ever since, with an increasing awareness and an increasing understanding of what disability rights are all about.

We are all hoping for a comprehensive UN convention on disability and you are representing South Africa in that process. What is the outlook?

I must say that sitting on the other side of the fence as government is a very difficult situation. I say it's difficult because as a disabled person I have aspirations. There are certain things I want to see in that convention. But on the other



The late Maria Rantho was deployed by Disabled People South Africa to direct the Disability Programme in the Reconstruction and Development Ministry in 1994, to draft the Integrated National Disability Strategy Green Paper. Maria was then redeployed in 1995 to become the first DPSA/ANC Member of Parliament. She was then appointed to the Public Service Commission by the President.

hand, as a representative of the South African government you need to reflect back on what our own legislation is all about and what the plans of government are with regard to disability, and sometimes the two – my aspirations as a disabled person and the aspirations of government as government – are not necessarily in sync. That certainly presents a dilemma.

However, I must say, as the one leading the process, I have a terrific team that brings on board both disabled and non-disabled people. I have Petronella Linders, the new Deputy Chair of the Youth Commission, and she brings a perspective that I find very useful. She is blind, while the rest of my team are government officials and are non-disabled. They have what I might call a decent understanding of disability and really want to be helpful, but at the end of the day they do not live with a disability. So, whatever their contributions may be, it's from a secondary perspective. My challenge is to balance the aspirations of disabled people with where the government wants to move towards. It is not an easy situation and I am constantly reminded by the members of my team that what I am promoting, much as it makes logical sense, from a government perspective is not realistic and therefore as a senior government official you cannot always be a proponent of a particular move.

That sounds a bit negative but, as far as a lot of the articles currently in the draft are concerned, South Africa is ahead. We meet regularly as a task team and sometimes we go through the articles and we say to each other: we've already been there, done that. That's very gratifying.

But we need to remind ourselves that this convention is not about South Africa. It's actually about the majority of disabled people who live on the African continent and it is their needs that we want to capture in the convention. And it be-

comes extremely difficult because most of the countries participating meaningfully in the process are in the north, while those who participate and reside in developing countries are people without disabilities who talk primarily as technocrats and bureaucrats. Their perspective is very different from what their own people with disabilities would present, if they had the opportunity.

Does the OSDP, and do you yourself have any role to play in the African Decade of Disabled Persons?

Our role as an office was to facilitate the establishment of the Secretariat for the Decade. About four years ago we were approached by the disability community on the continent for us to lead the development of the Decade; hence our role in convening a conference in 2003 that brought together representatives of government and civil society from all over the continent to deliberate on the African Decade. An offshoot of that meeting was the request to establish a Secretariat, recognizing the availability of good infrastructure and resources in this country. The South African government, through the President, agreed to that request and the OSDP was tasked with that responsibility and it has happened.

I am happy to say that Shuaib Chalklen is now officially employed as the CEO, on secondment from the South African government, which means an immense contribution of resources by the government by way of Shuaib's remuneration and support. The rest of the funding is currently provided by SIDA, but Shuaib is in the process of mobilizing more resources. Now that we actually have a Secretariat with its headquarters in Cape Town and a satellite office being negotiated for Midrand, all responsibility has moved to Shuaib and our role will merely be to serve on the board of governors and on the committee that oversees the Secretariat.

What are your own views on life and what are your outside interests?

I think my biggest hobby is raising two boys. I am a mother of two, eighteen and fifteen. Just that responsibility of knowing that you have these precious lives to look after and to nurture, to ensure that they grow into fine men, is a wonderful challenge. For me that is my only pastime; outside of that I don't have a life – I am still looking for one ...

I was born in Barberton in the then Eastern Transvaal, donkey's years ago. At ten months I contracted polio. It was 1957 and there was a terrible outbreak at that time. My mother didn't know it was polio, but I ended up in hospital with a very high fever and both my lower limbs became paralysed.

You're very close to the seat of power here in the Presidency. What is the political commitment like around here?

What has sustained this office since we started in 1996 has been the political will, and the political commitment, and the political support. Before 1999 we were in the Deputy President's office, but after that we moved to the newly established Presidency, which meant that we were directly under the head of state of the South African government. President Thabo Mbeki has been a very strong supporter and proponent of disability rights. He is the patron of the disability movement in South Africa and the disability movement is the only civil society formation where he has agreed to serve as patron. He has refused to take up any other patronages and you can't ask for any greater commitment than that. It's at a very personal level.

The same goes for Deputy President Jacob Zuma and the Minister in the Presidency, Dr Essop Pahad. The political

principals in the Presidency are strong supporters and proponents of disability rights. They go out of their way to mobilize resources and they talk about disability issues wherever and whenever they can. Minister Pahad has even embarrassed some of his colleagues in Cabinet by asking them directly how many people with disabilities are employed in their ministries. When I hit a barrier, I know that if I approach one of the political principals that barrier will be removed. All of this has been a major contributing factor to the success of the disability rights movement in South Africa.



The photograph shows Miss du Toit and SNAP Chairmen, Friday Mawani, on their way to a funding meeting in Johannesburg in 1981. SNAP attracted the support of social responsibility foundations linked to South African mining corporations to establish its first self-help factory in Soweto. This model was duplicated by other emerging self-help organizations of people with disabilities around the country in the 1980s, which became the membership base of Disabled

chapter 12

living in extraordinary

times

Interview with Mike du Toit



The photograph shows Mike du Toit and SHAP Chairman, Friday Mavuso, on their way to a funding meeting in Johannesburg in 1981. SHAP attracted the support of social responsibility foundations linked to South African mining corporations to establish its first self-help factory in Soweto. This model was duplicated by other emerging self-help organizations of people with disabilities around the country in the eighties which became the membership base of Disabled People South Africa.

From self-help to political activism, to economic empowerment; in each phase of the disability rights movement in South Africa, Mike du Toit was an agent of change. Here he gives us his account of 'an extraordinary time', and his future vision.

Mike, in this interview I want us to chart the course of the disability rights movement in South Africa. Of course, you played a part in that, in fact, several parts. Let's then start with yourself, before all of that.

Well, I became disabled in a motor car accident in 1972. I was a student at Rhodes University in Grahamstown, studying for a Bachelor of Commerce degree. So at the age of nineteen I got a spinal cord injury.

I went back to university after a year. It was a time of my own political awakening in the context of the South Africa that was then, and I think for me disability had the effect of making me want to immediately get on with something more relevant – which I thought might be social work. And I switched my studies from Bachelor of Commerce to a degree in Social

Science. I just felt life was too short, and perhaps too precarious, to be doing something I wasn't entirely comfortable with.

And so I qualified as a social worker. I worked first in the Crisis Clinic in Hillbrow. It was important for me not to work in the disability field immediately. I kind of felt that I wanted to establish myself outside of it, although I had a strong sense that I would work in it. Eventually I did start to work in it as a social worker for something that was then called the Cripples Care Association of the Transvaal.

It was a thoroughly frustrating experience. I had a sense that I and my fellow social workers were on very shaky ground. We really weren't at all sure what we were doing, and what the impact of what we were doing was.

| How did you break out of there?

I had this opportunity to go to the Rehabilitation International congress in Winnipeg in 1980. I was sent by the Quadriplegic Association of South Africa, which was perhaps an early version of the disability rights movement in that it was an organization largely controlled by people with disabilities. But they did employ me as a social worker and I went to that congress very much thinking of myself still as a social worker.

It was an extraordinary experience. One got there and there were just thousands upon thousands of people. Many were people with disabilities and, being in Canada, there were a lot of Americans, but people from other parts of the globe as well, and quite a few from developing countries. But people spoke so positively and convincingly about the disability rights movement that for me it was a fundamental change in perspective. I remember flying back to Johannesburg – my wife had been able to join me – and we were talking about the impact and all the experiences. And I remember saying

that it would just be the most wonderful thing to try and be involved in starting a disability rights movement in South Africa, but at the same time saying that, if that was going to be meaningful, it would have to be based in Soweto, having no idea that within six months I would receive a call from Friday Mavuso.

Friday was a black paraplegic from Soweto. He had been shot by the police in 1974 ... Sued the Minister of Police – the first black person, I believe, to have sued the Minister successfully. He was leading a group of eight paraplegics with the idea of starting what became known as the Self-Help Association of Paraplegics in Soweto (shortened to SHAP).

Of that group of eight, in fact six had been shot by the police. And one was struck by the difference: in my own experience, I stayed in the bar too long as a student and trashed my car.

These were people who never had cars, had never been to university, and their entry into the disability world was through the bullet of a police gun. So that's where I spent the next ten years.

Mike, I would like you to talk about SHAP in some detail, because in many ways it was the powerhouse of the early movement.

It was a project about employment and economic empowerment. It was run by the paraplegics themselves. Somehow we managed to raise some money so we could build a factory. We managed to establish links with the business world and we manufactured various things for the mining industry. We had different services we were providing – repairing cameras for Kodak, repairing calculators for Hewlett Packard, and all in all it was a remarkable story. The fact that it was happening in Soweto in the 1980's made it all the more remarkable.



The sewing section at the SHAP self-help factory, producing safety clothing for the mines. All machines, equipment and other aspects of the factory environment were adapted for use by paraplegics, and it seemed that there was little that they could not do.

SHAP's success was quickly recognized by the media. The media were government-controlled and in those days you had separate television stations for different race groups. TV1 was of course for whites and TV2 was for blacks, and the TV2 reporters kept coming back to SHAP week after week. They were looking for good-news stories in the townships, and the townships were effectively burning; so there was little that was good for them to write about in the way that they wanted to. So they kept coming back and as a result SHAP became very famous and Friday Mavuso became something of a legend in South Africa.

The effect of this was that disabled people from townships and rural areas across the country started travelling in to SHAP on a one-way ticket, having seen it on TV, having read about it in magazines and the newspapers. And all came with the same message: there was absolutely nothing where they came from and they were coming to get a better life at SHAP, which they had heard of.

And this is what gave rise to what we then called the emergent self-help campaign, where we would allow people to stay for a couple of months. They'd move in with one of the SHAP members – into their tiny Soweto houses – and they'd come to work every day. And the idea was that they would learn how the operation worked, what the philosophy was behind it; and then we would encourage them to go back and organize more disabled people around them and we would offer some sort of support. On that basis, within a couple of years we were supporting 40 or 50 emerging self-help groups across the country.

Is it true that people chipped in their disability grants to finance SHAP at the beginning?

No. What they did was they would work for six months. That was the rule: for six months they would work for nothing, apart from their transport and meals, and that was a kind of sweat equity to the project. The project couldn't afford to pay them in that time and they were working for something that would pay them later. They all understood that and in fact it served very well in terms of the sense of ownership that developed.

It was a remarkable project



A typical SHAP mini-bus, converted to hand controls so that it could be driven by a paraplegic driver. SHAP's fleet of vehicles traversed Soweto in the early mornings and evenings, transporting the members to and from work. In the daytime, they would do deliveries and collect materials for the factory, and at weekends transport members to sports and social events.

Their distinctive branding with the SHAP insignia ensured their safe passage in the turmoil of political unrest in the eighties.

And Friday was a remarkable leader, wasn't he?

Friday was a very charismatic leader. He'd really get the different sections of the factory competing with each other, stuff that today would be considered really good management practice. And he was doing it with just a standard two Bantu education; but of course he was a very wise man.



Friday Mavuso greets Bishop Trevor Huddleston, one of many dignitaries to visit him at SHAP in Soweto. Other visitors included representatives of foreign governments, multinational corporations, film stars and even Her Majesty, the Queen of England. Friday was a natural public relations expert, and all such events were widely publicized by his media entourage, which greatly added to his stature.

He used to call that his standard two university degree ...

He spoke about that a lot. He also had this ongoing battle with the social workers. He said they should never represent disabled people or ever speak for us. And he had problems with names of organizations, like the Cripples Care Association. He was forever threatening to sue them for defamation. It was ironic that some years later he was awarded an honorary masters degree in social work by the University of Cape

Town. We all thought it was a doctorate, but when it finally came through it was a Master's.

How did that initial groundswell translate into the mass movement that was to come in South Africa, and in the whole region, for that matter?

It was all these groups that were spawned by SHAP that then became the membership base for Disabled People South Africa when it was launched in 1984. We'd been having these disabled people's congresses for a number of years by then. They started off as to some extent white experiences, with white disabled people who wanted to work together, work against discrimination, arguing for accessibility and parking privileges, and a lot of focus on sexuality and disability. And we encouraged these groups to come to these congresses, and we knew that bringing in these groups of black people was going to change the nature of these congresses quite radically. And so it was in 1984 that we used one of those congresses to launch DPSA, which then became the voice of people with disabilities. It was certainly a hugely significant event.

You will remember, William, when we all approached you to be the first chairperson of DPSA, and we were absolutely thrilled when you agreed to take it on, because you added very greatly to the credibility of the thing. You were always a person who had a foot in both worlds: on the one hand, as executive director of the Council for the Blind you were something of a celebrity amongst the service providers, and on the other hand you were with the people on the ground, in DPSA and through your association with SHAP, and so on. And it really helped us to get past that first milestone, which was registration as a fundraising organization, without which we would not have been able to raise any money; and then

to get past the initial resistance of the service providers and the welfare organizations who controlled that system.

Thanks for that; those are generous remarks, but it really was very much an enormous team effort.

So we had become a mass movement of a lot of people in the country looking for real change around disability, but we had to recognize – and we did recognize at a very early stage – that the real change would only come once political liberation had been achieved. Before that anything would be cosmetic and ineffective. In many ways therefore we were in those days preparing for political liberation and the opportunity also to gain liberation around disability. And what we did to do that was to continue with the emergent self-help campaign, with the idea of building the movement in terms of numbers.

We realized that if we were going to be credible when the democracy process started, we needed to be representative across the country and we needed to have the movement thoroughly rooted in black townships and rural areas, and that was very much our focus. We also started leadership training and projects like RURACT, to mobilize disabled people in the remoter areas, and of course Discrimination Watch, as we were discovering for ourselves and gaining an unfolding understanding of what human rights were all about.

We were very much helped along by the establishment of the Southern Africa Federation of the Disabled (SAFOD) and the involvement of Joshua Malinga, who served two terms as President of DPI, Bulawayo-based. We were privileged, somewhat oddly, given the political circumstances of the time, to actually launch SAFOD in Durban in 1986 and, again, you were the first chairperson and you will remember this well.

No; we felt the first leader should be a black person, and then, when Trofomo Toso of Lesotho disappeared, I took over, a year or so later.

Okay; and I wonder if you remember Joshua's famous speech to us on the occasion of the launch. Zimbabwe had already experienced its political transition and he was speaking to us as South Africans, telling us that sooner or later it would come, the political process would happen. And I remember him warning us that it would be chaos, and his advice to us was to be sure to be part of the chaos.

And our leadership heard that message and – in the early 1990s when the political organizations were unbanned and the negotiations for the new democracy started, and even in 1994 when the first elections were held and in the period immediately thereafter – there certainly was a great deal of chaos around, and we were very, very much part of that chaos. We were accepted into the constitutional negotiations as part of the Patriotic Front against Apartheid. We were part of the political demonstrations and the conferences about this or that; whether it was about women, or about race, or about economic empowerment, we were always there raising the disability factor.

I believe that was absolutely essential in getting the position that we subsequently gained in our new democracy. And the real uniqueness of it is that we really have managed to integrate disability into mainstream policy. We looked at the different models around the world and we decided, rather than going the route of the disability act, we would try for what in our view was one better, and that was real integration. So what we have is that in every piece of legislation, whether it be on culture, language, education, labour relations, or economic empowerment, disability is specifically included and the way that act will address disability is spelt out. Then of

course we also now have the Equality Act, and that is another example of how disability is featured.

| At what point did you become the Secretary General of DPSA, and what were the circumstances?

After serving ten years with SHAP in Soweto, I had pretty much done anything I could that was useful. The last thing that people hadn't learnt was how to type, and I was sitting there typing letters, and so it was time to move on.

At that stage we had decided to create the post of Secretary General in DPSA. I resigned my job and took the new one, and then I had to start to raise the money to pay for the position. That was at the beginning of 1989, and I had to build DPSA into a working organization, with very much more staff capacity, and within a few years we actually had offices in all the provinces.

| I think it would be of interest to sketch the developmental structure that we established in DPSA.

When we first started DPSA, membership was open to groups as well as individuals, but there was a lot of pressure from many quarters to make it more structured, to look at the equitableness of membership, and accountability issues. And what we finally came up with was a structure where in each province the membership became the groups – self-help groups, advocacy groups, and so on. They would come together in something we called the Provincial Development Team, like a provincial council. Each group was represented by two people; they had to be of different disabilities and at least one had to be a woman.

From there the provincial councils would put forward people into the National Congress, at which the DPSA Council was elected. Again, that was made up of two people from each

province, of different disabilities, and at least one had to be a woman. And then, to increase the representivity still further, there were positions reserved for under-represented groups, for example, people with mental disabilities, deaf people, and people from rural areas. And so the thing became a lot more formal and a lot more bureaucratic, but I suppose that's development.

| What about the broader movement in the region?

I was less involved there, but, yes, we should refer to that. The regional movement was interacting internationally, and one effect of the regional movement was that we were exposed to this developing philosophy internationally and to the instruments of the United Nations, such as the Standard Rules, which became our Bible. When we spoke to government, we structured our thinking very much around the Standard Rules.

And then in the context of Africa, South Africa is quite a developed country, while most of our neighbours are very poor. It was through SAFOD that we got exposed to what was happening and to the part our neighbouring countries were playing in the liberation of South Africa. It was certainly an experience which not many white South Africans were having. One really understands today the emphasis President Mbeki gives to African development, to the whole concept of NEPAD and getting things right in Africa. We are part of Africa and there's no prosperity or future for us if Africa doesn't have its chance.

| And now your full-time involvement is in the economic sector.
| Less a career move, perhaps, than a natural progression?

One of the strategies in DPSA was to give different people focus areas to work on. So we had people who became spe-

cialists in education, in social security, in housing – and my particular interest was in economic empowerment, that was always the theme that I paid attention to. The idea was that these people would gather information from whatever source, internationally or locally, and try to be part of the discussions, debates, and campaigns around those specific issues.

When I worked in Soweto I saw the effect of just a little bit of economic empowerment on people's lives – so that's been a priority for me. At the moment, I work very much in the area of black economic empowerment as CEO of the Disability Employment Concerns Trust (DEC), and we continue with our advocacy in the sense that the black economic empowerment policy framework is a priority of government. The political struggle has been won, but the majority of the people remain poor. The policy framework therefore seeks to progressively achieve the transfer of assets and management control to the majority of the population, with special emphasis on race, women, and people with disabilities.

The way the process works is that, when government can influence the economy, it does so in a way that these targeted groups have some special advantage, or at least the opportunity to participate. If the government, for example, issues a licence for a second national telecommunications operator, it will specify in the criteria for the awarding of that licence that there should be significant participation of black people's businesses, of women, and of disabled people's businesses, and that creates the opportunities. Take the different sectors: in the petroleum sector, for example, they have, together with the captains of industry, proclaimed a charter which has the target that 25 percent of that sector should be controlled by black people within ten years. And there will be similar charters in mining, financial services, and so on.

What's a typical working day like for Mike du Toit?

That's an interesting one. It's from meeting to meeting ... At DEC we have a strategy to have at least one main investment in each of the economic sectors, and for the companies we invest in to become role models for disability economic empowerment in that sector. Their premises must be physically accessible to disabled people, they must employ disabled people beyond the requirements of the Employment Equity Act, and they must have good skills transference programmes.

The effect of this is that in a day one could go from a meeting in the mining sector over to another in media (where we have shares in Classic FM, a radio station), over to something in gaming (where we have shares in the national lottery operator), over to another meeting in banking (where we have shares in the third largest bank in South Africa, Peoples' Bank), and so on – to manufacturing, to telecommunications (where we are hoping to be part of the second network operator), to public/private partnerships in construction (where we are included in a bid to build a rapid rail link, a really sophisticated new rail system for Gauteng), or designing, constructing and managing government facilities, companies in the Electricity Supply Commission stable ... Moving from one sector to another by the hour, virtually.

What for you have been the real achievements of the disability rights movement in South Africa?

I think the big one is that we really have begun to succeed in creating a mind shift among disabled people themselves, but also, very importantly, amongst the policy-makers, away from disability as a health and welfare issue only, over to one of human rights and development, where there is a very real and significant attempt to integrate disability into all sectors of

South African life, from representation in parliament, through the Office on the Status of Disabled Persons in the Presidency, to the provincial premiers' offices. Things are moving quite rapidly at local government level as well and, as I've said before, in each piece of legislation coming through, disability is there, and, generally, in a pretty sensible, meaningful, and, I hope, achievable way.

The other one is economic empowerment. We have a remarkable situation and I think it will happen increasingly that disabled people will come away, in years to come, as owners of significant assets in the South African economy. Policies may come and policies may go, but that participation should be something that stays and promises to be a useful and significant source of income in the future.

How do you see our future direction?

It's a very interesting phase that we're in at the moment. There was a period – perhaps the first five years after the democratic elections of 1994 – that there was a great deal going on. The new government had the task of literally rewriting every policy in the country, rewriting it to correct the inequalities of the past and bring South Africa into the mainstream of the world. So there was a strong focus on international best practice, and so on. And we were fighting to get disability involved with all of those things. It was an incredible opportunity: there were struggles and victories every day and every week and every month.

Now things are a little quieter. To a large extent the policy framework is in place. The legislative framework is unfolding, the bigger part has probably been achieved, but there's still some to come. We're already, in many cases, into our second generation of leadership in key government positions. We've been through our second election at national and

provincial levels, and new politicians have come in. There's been a turnover of staff in the OSDP and things now are happening almost automatically – the principle has been entrenched.

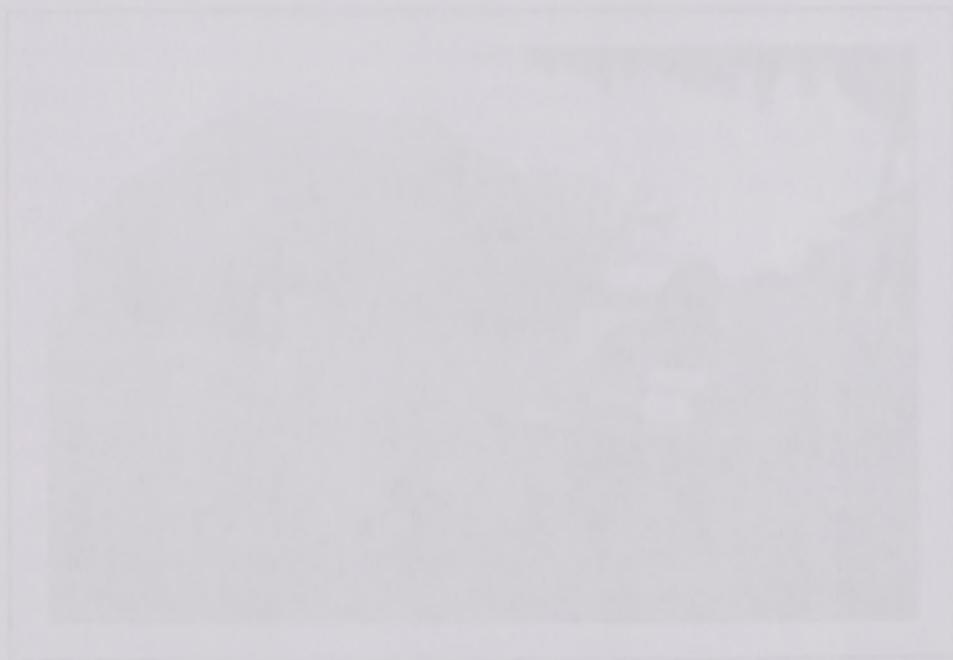
At the same time, one does become concerned, because the struggles are far from over. Making all the good stuff work in practice for real people really does require that the movement be as strong as it ever was. There's almost a sense that we've arrived, that we've achieved what we set out to do – and it's very true in many ways – but I'm not sure that we fully understand what our task is now to make it all stick. But what we've started is not for today, it is for future generations. Over the long term new generations of disabled people will see this being implemented. I certainly think we have started something that is pretty much unstoppable.

Mike, I am fascinated by the fact that when I speak to the people of the first generation of our movement, there is a tremendous nostalgia for those early years ...

William, that was a very special time, and I think it was a special time for all South Africans. It was an extraordinary time to be alive. A country that was on its way to rock bottom and to go to the lengths of violence and destruction that were inevitable, and suddenly we turned around.

And then it all worked and we had a democratic government and that government was developing policies and legislation based on international best practice and trying to reduce the effects of the apartheid era. And we had the opportunity to be part of all of it. And that was the real trick of the disability movement, recognizing the opportunity and taking full advantage of it.

It was much easier – although it didn't feel easy at the time – to have the impact we did in a situation of such general change and revolutionary thinking. It would be difficult to imagine achieving anything like it in an Oslo, a London, or a New York, where, until recently, things have been very much the same, year after year, decade after decade. It was a time of change and we were greatly privileged to be part of it.



Conditions experienced by the author in the rural areas around Mangoni Hospital, Jamaica, in the 1970s. This experience directly contributed to the prioritization of a rural focus in the disability rights movement in subsequent years, strongly advocated by the Rural Disability Action Group (RURACT).