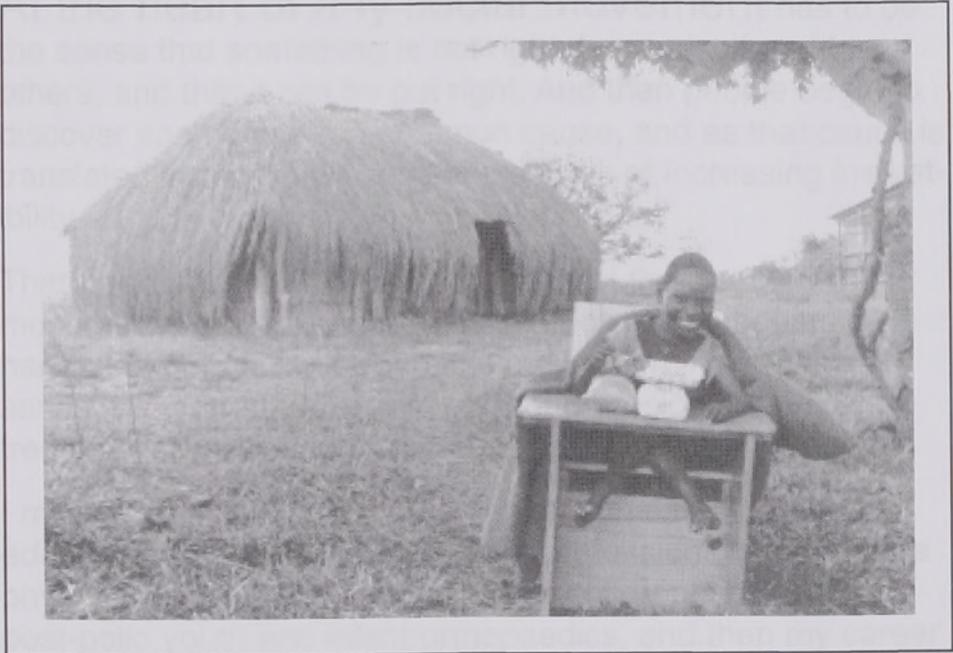


chapter 13

building a

movement



Conditions encountered by the author in the rural areas around Manguzi Hospital, Zululand, in the eighties. This experience directly contributed to the prioritization of a rural focus in the disability rights movement in subsequent years, strongly promoted by the Rural Disability Action Group (RURACT).

At the heart of any social movement has to be the sense that something is not right, for yourself and for others, and that it can be put right. And then people begin to discover each other in a common cause, and as that cause is translated into action it becomes a force of increasing irresistibility.

That's certainly how I see the genesis of the disability rights movement in South and Southern Africa: at the beginning a handful of activists; later a mass movement of many thousands, brought together by accident or design, from the extremes of poverty and violence.

I myself came down the more conventional track of a good education at a school for the blind, professional training as a physiotherapist in London, work in a children's hospital with post-polio youth and infant orthopaedics, and then my career at the SANCB, first in fundraising and public relations, and, after increasing self-involvement in rehabilitation and other programmes, as executive director, from 1976 onwards.

And then the fork in the road ...

In 1981 the United Nations declared an International Year of Disabled Persons, but sanctions-isolated South Africa refused to recognize the event, because of its antipathy towards the UN. When our protestations went unheeded, we decided to celebrate the IYDP with our own national conference. What stands out in memory from that occasion is a presentation by a young occupational therapist, Pam McLaren, on an outreach programme at the Manguzi Hospital in the far northeastern corner of KwaZulu-Natal, on the Mozambican border. Most striking was the plight of over 3000 people with Mseleni Hip Disease, which had reduced their mobility to painful crawling.

Straight after the presentation I introduced myself to Pam with a simple question: would she, if I found the funds, include blind people in her outreach work. She immediately said yes, but a few days later she attached a prior condition: I would have to spend a week on the Makatini Flats to learn about rural conditions, or to be 'sensitized', as we might say today.

It was a week of personal awakening. By day we went to pension pay points with the community health workers to talk to people about their problems, and visited people in their tiny thatched reed homes to find out how they lived. To my question 'how are you?' the answer was unvarying: 'I am hungry.'

In the evening Pam would cook a meal and take out some wine, while we discussed at length the experiences of the day. We debated the possible causes of Mseleni Hip Disease and concluded that it had to be the outcome of harsh living conditions. The sufferers were mainly women and they were the ones who every day, over many years, had to trudge to distant wells or rivers to fetch back heavy containers of water for family use, balanced on their heads.



Mseleni Hip Disease, a painful mystery condition affecting mainly women in the Manguzi rural area, considered to be caused directly by harsh living conditions.

I joined a local family to observe their daily routine, from early morning till late afternoon - the fetching of water, the tending of children, the coming and going of neighbours, the collection of wild plants for relish, the grinding of mealies in a wooden stamper, the winnowing of the grain in a winnowing basket, the collection of wood for the fire, and the making of putu for the evening meal; but I realized that this was no ordinary day for them when I was given cake, their offering to an honoured guest. These were of course mainly women, as the men would be migrant labourers.

At the hospital I examined with my hands the limbs of a woman with leprosy – no fingers, no toes; just blunted stumps.

In translation I listened to her story as a disabled Mozambican refugee. Renamo rebels had attacked their house, killing all the men, and raping the women on top of the dead bodies. Somehow she had escaped with her injuries and her life over a landmined border into South Africa.

At Zamazama I met with a group of twelve unemployed blind youths. Their leader was Zacharia, also known as Isikhindisemali (the short pants with money in his pockets), because of his uncanny ability always to earn a little cash by singing his songs to the accompaniment of a homemade guitar. He had remarkable mobility skills, being able to walk unaccompanied over long distances in rural terrain, simply by following the natural landmarks. None of these young people had ever met a disabled person who was employed. How could they themselves find work?

My visit to Manguzi was the beginning of an unspoken partnership with Pam that lasted many years, I, the theoretician, she, the practitioner. What emerged was an initiative to implement community-based rehabilitation (CBR) in South

Africa according to the precepts of the World Health Organization. At the community level was the rehab worker, several of whom were co-ordinated by a health professional at the district level. Also at the district level was a referral hospital to deal with surgery and difficult cases.

The key was the rehab worker who had to train family and community members in what to do when someone couldn't see, couldn't hear, couldn't speak, couldn't walk, or showed 'strange behaviour', to use the WHO terminology of the time.

What we soon learned, though, was that each situation had to be approached with utmost flexibility and that the rural initiative had to include solutions of income generation. Over time there developed a network of some 200 individuals and projects engaged in rural activities ranging from rehabilitation work in the community to self-help enterprises – one of them at Zamazama. That which had begun as the Rural Disability Action Group ended up in 1986 as the organization RURACT.

While the objectives of RURACT were personal independence and income generation, through training and self-help, there was another outcome that, looking back, I think was even more important: the mobilization of disabled people in rural areas. It meant that the groundswell of activism across the country, spearheaded by DPSA and its urban leadership, could link up with parallel processes in the remoter parts of South Africa. However, it also meant conflict between disability leaders and the professionals, attacks and recriminations, which left many therapists and social workers angry and disillusioned. Some fled the scene, but there were others who well understood their enabling role and the absolute necessity of self-representation.

It would be a mistake to regard this attack on professionals – and by extension on service providers – as just a minor as-

pect of the political struggle that was unfolding on every side. Disabled people felt that the very system that was supposed to alleviate their circumstances and provide them with a means of livelihood was in reality a barrier to their progress. That, then, was where change had to begin.

But the majority of disabled people were also black and therefore experienced the effects of poverty and racial discrimination first-hand in their own lives every day, a situation made worse if you were a woman and doubly worse if you were disabled. And so the rising militancy all around, from the fight against apartheid, spilled over into the disability rights movement and gave it its liberation aspect.



Alexander Phiri (left), Secretary General of the Southern Africa Federation of the Disabled (SAFOD) was a driving force behind the development of national disability movements in the Southern Africa region in the 1980s and 90s.

This was also true of other countries in the region. In Zimbabwe a war of liberation had ended with independence in March 1980 and many of the disabled people there were war veterans, while everybody had inherited the attitudes and vocabulary of the political struggle. There existed a natural affinity between the disability leaders of Zimbabwe and South Africa and a special relationship developed, a kind of two-country axis to drive the struggle of disabled people across the subcontinent.

At the founding of the Southern Africa Federation of the Disabled in Durban in 1986, Zimbabwe, South Africa, Zambia, Namibia, Lesotho, and Botswana were represented. The SAFOD headquarters were established in Bulawayo and it was there that I attended my first cross-border congress. Alexander Phiri, who would later become our secretary-general, opened the congress with a rallying cry: 'Comrades in the struggle for social justice!'

There followed a revolutionary address such as I had never heard before. And then, when President Robert Mugabe failed to show up, it was my turn, as his somewhat bewildered substitute. My greetings from the movement in South Africa were well received, as was my message of solidarity.

Our strategy in SAFOD was to activate and support disability movements in all ten countries of the region and our handbook was the World Programme of Action Concerning Disabled Persons. This UN instrument, adopted in 1982, proposes practical measures to be implemented by governments in the fields of rehabilitation, prevention, and the equalization of opportunities. Rehabilitation and prevention, we argued, were indeed the business of government, and sometimes NGOs, but the equalization of opportunities was our domain, our agenda to be negotiated with policy-makers in government.

Funds were found to promote the World Programme of Action and the mechanism used was two-country seminars, to allow for the sharing of experience and the interaction of membership. We had rules about the participation of women and to ensure the regular inclusion of new delegates, and events were always attended by one or more of the SAFOD leaders – Joshua Malinga (our mover and shaker), Alexander Phiri, AK Dube, myself, and others. Also, there were the biennial SAFOD congresses that rotated around the region and the founding rallies of the stronger movements, sometimes attended by cabinet ministers and, in one instance, by President Sam Nujoma of Namibia himself.



Moses Masemene, blind lawyer and founding leader of the disability movement in Lesotho, and the Executive Director of the African Union of the Blind (AFUB), Thomas Ongolo, at a SAFOD seminar.

Moses went on to become Minister of Justice in Lesotho.

The movement seemed to take a firmer hold more quickly in those countries familiar with liberation-style politics, such as Zimbabwe and Mozambique, whereas it proved extremely difficult to go beyond first individuals in countries with traditional or dictatorial regimes, for example, Swaziland and Malawi. Lesotho was an exception, perhaps because of its close connection with South Africa, but also because of the strength of the founding group, ably led by blind lawyer Moses Masemene, today Minister of Justice in that country. Angola remained a hopeless case because of the civil war being waged there, a civil war that ended only in 2002. Maybe their turn has come at last.

Running programmes from a regional level was often problematic, although two initiatives did, in my opinion, show returns – grass roots development and, particularly, the women's programme. Here I give credit to AK Dube, our programme director and a formidable fundraiser, and to women leaders such as Susan Chitimbi, now Minister Responsible for Disability Affairs in Malawi, and Maria Rantho, recently deceased.

Disabled women, on the widest possible front in Africa, felt themselves to be unwanted and abused and marginalized. Therefore SAFOD women's seminars were about strengthening self-image, taking charge of your own life, and demanding representation. Men were excluded, unless invited in, and when this happened it often turned out to be a harrowing experience. Men were also commanded to keep their distance and it became regular practice to read out a sexual harassment warning at the commencement of SAFOD gatherings.

While self-help projects were few and far between outside of South Africa and Zimbabwe, we did produce very useful training materials for the setting up of these worker co-ops.

Emphasis was laid on a fairly lengthy process of preparation, to allow the group to bond and natural leadership to emerge, and of course on careful planning and selection of products for manufacture. Record keeping and the basic principles of management were also taught, with much stress, in the latter case, on consultation and democracy within the group. Leadership skills were taught in their own right.

As Chairperson of SAFOD I from time to time carried out country tours to learn about local conditions and make contact with the membership. It meant visiting projects and consulting with groups, but often individuals would turn up unexpectedly at the hotel or be waiting at the arrival point and they, too, would expect to discuss their problems. The itinerary included media interviews, and always one or more meetings with senior government representatives to explain the role of the national movement and hand over copies of the World Programme of Action.

One of the most memorable of these tours was through Mozambique, in the company of George Tinga, a university lecturer and a man of great dignity, dignity that was sorely tested the day of our interview with Dr Simao, the Mozambican Minister of Health.

Arriving on time for our afternoon appointment, the delegation was dismayed to find the elevators out of operation because of a power cut. 'What do we do now?' I wondered. 'Let's go,' said George, slipping out of his wheelchair onto the floor and launching himself on a six-storey slide on his buttocks up the stairs, in his best suit.

None of us will ever forget Dr Simao's first words to us at that very successful meeting: 'I am your enemy. Convert me!'

'Mr Minister,' I said, 'the fact that you say that means you understand our problem.'

South of the capital, Maputo, was a camp accommodating around 2000 disabled war refugees, living in tents on the bare ground. In one of these tents I met with nine blind people to learn about the Mozambican movement's first project, the equitable distribution of food in the camp so that the blind people could get enough to eat. Paolo, the only one able to speak English, slept on a bed frame without a mattress, all his worldly belongings in a cardboard box underneath. 'How long have you been here?' I asked. 'Nine years,' he said. I was appalled, and astonished to find that he still had a plan for his life.

Outside the northern coastal city of Beira, we visited a self-help project where they manufactured coffins. It was a very hot day and on the drive back George and I fell asleep in the car. We were awakened by a thunderclap of sound off to our left. 'Renamo rebels,' was my instant thought. 'The shot of an AK47 rifle?'

A blow-out of a worn tyre on our vehicle was the explanation.

In Beira we put up at a government guest house, by official invitation. A beautiful old colonial mansion all to ourselves, and two cooks. We ate well and, on the insistence of our hosts, I entertained a sizeable group of the local comrades to dinner. It was a sumptuous meal, with South African wine, and even a little brandy appeared on the table.

Our shock came the next day when we were handed the unanticipated bill. We said that we had no money to pay and set off for the airport, with the cooks in pursuit. We were still arguing as we passed through the barrier to board our flight.

At some point SAFOD acquired a genuine London taxi as a means of transport and it was in this antique vehicle that Alexander Phiri and I rattled across Zambia, with a group from the local movement. Arriving late one evening in Ndola

in such an unlikely conveyance made us very conspicuous, which possibly triggered the incident that followed.

We were given shared rooms in a derelict training centre and it was there, sometime after midnight, that we heard heavy boots coming down the corridor and a loud knock at our door. 'Where is the white man?' a voice called out.

It was Alexander's presence of mind and adroit handling of the situation that averted serious trouble. Our visitors claimed they were security guards, but were unable to repeat their identity numbers after passing their cards underneath the door. Alexander then resorted to teasing and banter until they went away.

Another incident in Ndola makes for a more poignant memory. It was our meeting with an old man, Mr Chimanya, who had travelled to see us from the remote Luapula Valley in the northern part of Zambia, his sole purpose being to extract from us a promise to visit his people and talk to them about possible livelihoods, which he thought might be fishing in Lake Bengueulu or weaving with local grasses. When we had not yet arrived in the town, he put up in a bus shelter for three nights until we came.

So, these were some of our adventures, but the point of it all was to spread the message that by organizing ourselves we could change things around us and the attitude of governments. This we have continued to do everywhere in the countries of South and Southern Africa for twenty years and more, and yet the process is far from ended.



abbreviations

that may be unfamiliar to some readers

ADA	Americans with Disabilities Act
ANC	African National Congress
BEE	Black Economic Empowerment
DEAFSA	Deaf Federation of South Africa
DEC	Disability Employment Concerns Trust (recently converted into the company Disability Empowerment Concerns)
DICAG	Disabled Children's Action Group
DPI	Disabled Peoples' International
DPSA	Disabled People South Africa
IFP	Inkhata Freedom Party
INDS	Integrated National Disability Strategy
IYDP	International Year of Disabled Persons
NEDLAC	National Economic Development and Labour Council
NEPAD	New Partnership for Africa's Development
NOBSA	National Organization of the Blind in South Africa

OSDP	Office on the Status of Disabled Persons
PAFOD	Pan-African Federation of the Disabled
RDP	Reconstruction and Development Programme
SAFOD	Southern Africa Federation of the Disabled
SANAC	South African National AIDS Council
SANCB	South African National Council for the Blind
TRC	Truth and Reconciliation Commission
WHO	World Health Organization



words

that may be unfamiliar to some readers

Combi	A mini-bus
Flat	An apartment
Gauteng	One of the nine provinces of South Africa
KwaZulu-Natal	One of the nine provinces of South Africa
Mealies	Maize
Putu	A thick porridge made from ground maize
Sangoma	Traditional healer
Transvaal	One of the previous provinces of South Africa (now divided between Gauteng and adjacent provinces)



Dr William Rowland's book *Nothing About Us Without Us: Inside the Disability Rights Movement of South Africa* is an inspirational work written by an authentically inspiring author. Only someone who is at the same time a leader, a disabled person and a truly committed person could have produced a work of this import. The book offers something of everything: it is an insider's tale, a human tale, a tale of triumph over adversity, a tale told by an experienced expert and a tale of the triumph of the human spirit. It is above all a readable, accessible book that should appeal to a wide variety of book lovers.

A glance through the table of contents reveals a lively, dynamic title for every part of the book. Reading the text itself uncovers the delights that can be imparted only by that rarity – an authority that can really write. There is no sentimentality here, only clarity in the exposition of the world of disabled people and their struggle to be seen as ordinary, useful and, as with all human beings, sometimes exciting people.

Dr Rowland writes of these people with deep understanding, whatever their disabilities may be, highlighting their often innovative and heroic efforts to have an independent voice and be accepted for their humanity. The story he tells is first and foremost a story of achievement, not achievement within the confines of the narrower rules sometimes prescribed by the unknowing for disabled people, but achievement defined by any rules. A careful reading of the book discloses that it is not that the disability movement in South Africa has nothing more to fight for, which would be too idealistic. Rather, the movement has pulled off a coup on the open playing field of life, where reality and ideals so often clash.

The book can be recommended to experts and laypeople alike. No one who has read it, can fail to have his or her conscience pricked. No one who has read the book can ever see a disabled person in quite the same light again.

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