

Health and disabled women

by Critical Health.

This article looks at the experience of disabled people in South Africa. It suggests that the quality of life for disabled people is influenced in an important way by the attitudes of others to disability. It looks at how disabled people are treated within the health care system focussing on the problems of disabled women.

You could be deaf, you could be blind.

You could have a speech impairment.

You could be physically disabled, having no use of your legs and feet and forced to rely on your hands and arms to move yourself around. If you are lucky you might have a wheelchair.

You could have cerebral palsy, or multiple sclerosis, or some other disease which cripples one or other of the functions of your body.

You could be mentally disabled. Perhaps this also contributes to a speech impairment. Perhaps your mental disability makes it virtually impossible for you to learn to read or write, or even count.

Maybe age has started to take it's toll on you.

Perhaps when you were born you were already severely disfigured.

It could have been the result of a slight error of judgement by the doctor who was taking care of your mother when you were born.

Or an accident on the road.

Maybe you were raped and brutalised by some thugs - or shot by the police in the riots in 1976.

Or a few years ago your boyfriend was in the SADF in Namibia and a landmine exploded virtually under his feet.

According to UN statistics, on average 10% of the population of every country is disabled. The Department of National Health's 1987 report on disability in South Africa notes that 12,7% of South Africans are disabled. (1987; Vol. I, p.14) (These statistics do not take into account the "independent homeland" populations).

The experience of disability

But what does disability mean?

The World Health Organisation (WHO) makes the following distinction:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability: Any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being. (UN Action Program, 1983:3)

Access

So if you're disabled one big problem may simply be that of getting access to places, your doctors rooms, the hospital or family planning clinic, for example.

You may be a physically disabled person who actually can't get to the hospital without accessible public transport. Or you may have learning disabilities and when you get to the hospital, you are sent to stand in a long queue. After waiting in the queue for the whole morning you finally get to speak to someone. They get impatient with you because you can't immediately answer some of their questions. They send you away telling you to come back with someone from your family.

Maria Rantho

Disabled People South Africa (DPSA) is an organisation of disabled people which deals with disability rights issues. One of their more outspoken members is Maria Rantho. Maria grew up in Mamelodi where she passed Matric in 1973. She trained as a nurse, working at Tembisa hospital until her spine was fractured in a road accident. Subsequently she has lost the use of her lower pelvis and her legs. She stays in Garankuwa and works in Soshanguve. She has a ten year old son who was conceived and born after she became disabled.

About the problem of access to buildings Maria says, "you sometimes fear to go to such places because you won't be able to reach who you want to reach. When you look at the set-up in our hospitals they've been designed to accommodate non-disabled persons. There are certain areas where I for example cannot reach. As a result you fail to get adequate health services." If you are staying outside of the city, and have to travel long distances to get to a hospital or clinic, this problem of access becomes much, much worse.

Admission to a hospital doesn't necessarily mean an end to your troubles. "The high beds with wheels, narrow bathroom doors, and small bathrooms," were amongst the



Mozambican war victims - war and violence have added considerably to the number of disabled people in Southern Africa.

difficulties experienced by one disabled woman in an American hospital. Said another, "I couldn't get the tops off the food with my atrophied hands. I couldn't properly wash myself because I couldn't squeeze out the washclothes, hold soap or reach my legs. I was forced to use a bedpan because I couldn't walk on the highly polished floors". (Crabtree, 1990; p.4,5).

Disability grants, education, employment

If you're disabled you may get a government disability grant. But this doesn't add up to that much, and if you're black it's less. There are various assistive devices which you can get, a wheelchair for example, but they may be far too expensive.

There's the problem of getting an education and of finding employment. According to a Human Sciences Research Council Survey, only 10% of South Africa's disabled people have permanent jobs. (Star, 20/9/89). In some countries regulations define a quota of disabled who must be employed by larger businesses. But even this is a source of controversy amongst disabled people. Some argue that they would rather not be employed by quota because they are disabled. Rather they would prefer the opportunity to prove themselves and to be employed on merit.

Living through pain

Perhaps your body is racked by excruciating pain and being alive is virtually unbearable. There may be those amongst the ranks of the disabled who feel there is no point in going on living. In 1990, 31-year-old American quadriplegic, Kenneth Bergstedt, petitioned the Las Vegas courts for permission to be given a sedative, have his life support system turned off and be allowed to die in peace. According to an affidavit, Bergstedt, who has been linked to a respirator for than 20 years, "receives no enjoyment from life, and is tired of suffering".

But, Paul Longmore, an assistant professor at a US University who also uses a respirator, is critical of cases such as Bergstedt's. The reason why people such as Bergstedt feel that they have no hope, "is not fundamentally because of their disability, it's because of their social situation". Actually, he says, "there is nothing inevitable about the social isolation and the deprivation of self determination of even the most severely disabled people". (Johnson; 1990a, p.19)

"Other people"

Which means that the experience of being disabled has got a lot to do with the way that other people treat you. There are those who mock, who bully, who laugh at you. There's the loneliness, the isolation, just being ignored by other people. Says Maria Rantho, "basically people treat us as people who are really sick and cannot do anything for themselves.

It may start with your family. Says Maria, "People are ashamed to have a disabled child in their own home. We are viewed as people who must be hidden away within our own families."

She continues, "If you look at the rate of illiteracy among disabled persons, that starts from the family itself, from not really accepting the disabled child as someone who can be sent to school and can be educated and can be somebody in his community."

"And when you look at people in general, whenever there's a disabled child in the family, it has certain connotations [for them] as if maybe you have been bewitched or [it is] a bad omen. As a result you are isolated from the rest of the community for just having a disabled child."

Even the non-disabled child of disabled parents may be singled out, blamed and stigmatised, because of the disability of his or her parents.

Referring to her own experience as a disabled person, Maria says, "I'm taking particularly about black disabled people or children. In the sense that our culture doesn't accomodate disability. It's only now that disabled people are actually living to a certain life-span but previously, you realise, they were killed for being disabled."

"Society still treats us as if we don't exist. But," says Maria, "we've got a right to live,

a right to express ourselves."

Health care

These attitudes are reflected in the attitudes of health care workers. "They can discuss you as a patient in a hospital, without taking into consideration the fact that you are there, just talking as if they are talking about a third or fourth person, not really consulting you in anything. The result is that they can take any kind of decision without actually telling you that this is what is happening with your body, or with you."

Says Linda Crabtree, about herself and another disabled woman, "I realised that her hospital experiences paralleled mine: lack of sensitivity, not listening to us to learn how things have to be done (after all, we're the experts on us), ignorance of any underlying conditions relating to our disabilities and how we must cope, and a disregard for the patient's basic sense of dignity." (1990, p.4)

Being alive

On another level these attitudes are also relevant in relation to decisions, made by people, women, health care professionals, others, as to whether to abort a child. Says Mary Johnson, writing in *The Disability Rag*, a magazine written by disabled people,

"This is not a discussion about a women's right to choose. It is a discussion about the thinking that prompts the woman, or the couple, to make certain specific decisions based on cultural assumptions that have been shaped by discriminatory practices and attitudes - against disabled people. A decision to abort based on the fact that the child is going to have specific individual characteristics, such as mental retardation.....says that those characteristics take precedence over the living itself. That they are so important, and so negative, that they overpower any positive qualities there might be in being alive." (1990b, p.34)

Disabled women

For disabled women, these problems, problems based on other people's attitudes and assumptions, affect all aspects of the health care that they receive.

Sexuality and contraception

So when you speak to the family planning nurse about contraception she may be horrified at the idea that someone in a wheelchair could even think of having sex.

"You know if you go and seek contraception," says Maria Rantho, "it will be as if you are under cross examination. 'What are you going to do with this?' 'Hey you are naughty, you are silly.' Who told them that as a disabled person I cannot fall in love? Who told them I cannot be involved in a sexual relationship?"

Whilst one problem for a disabled woman may be that health workers refuse to accept that you can be involved in a healthy sexual relationship, and regard giving you contraceptives as a way of encouraging irresponsibility on your part, another problem may be when contraceptives are forced on you without your even being consulted.

Depo Provera

You have some kind of brain damage which in some way impairs your speech. The nurse is aware that you are sexually active because you have a sexually transmitted disease. Next thing they have stuck a needle into your arm. It contains Depo Provera, a contraceptive. As a result of the side effects, you don't menstruate for three months.

A problem which is experienced by all disabled people, particularly the mentally disabled, is that you are often treated as if they you have no decision making ability. Health workers are often inclined to be paternalistic and assume that they need to protect



Brain-damaged child with loving grandmother - disabled children are sometimes discriminated against within their own families.

the disabled. In fact they may be preventing the disabled person from taking responsibility for his or her own life.

Motherhood

The question of motherhood may be another source of contention. Says Maria Rantho, "I fought with one doctor. He was nasty and arrogant and insulting. I was pregnant. I was disabled. I was on a wheelchair. He didn't take me as a human being, he didn't take me as a woman in the first place. He wanted to know who the bloody hell that guy was. And it's the very same guy who [I'm now married to.] We've got a very beautiful relationship. We've got a right of deciding whether we want to have children or not. That's very personal. It doesn't have anything to do with anybody else."

"For the fact that I'm disabled I am viewed as someone who can not be a mother, who can not look after anyone. I am looked at as someone who will be a patient for the rest of my life. That connotation will always be attached to me as a disabled person. I will never be able to get away from it because that's the way society, the way medical professionals, the way everybody views me, as a sick person you see. And boy I'm telling you, many of us are well capable of looking after our own lives as well as the lives of so many people who are not disabled."

One of the assumptions that people make is that the child of a disabled person will also be disabled. In certain instances, it is true, disabilities are passed on as a result of genetic factors. It is believed that 25 to 30 % of blindness, for instance, is caused by hereditary factors. Genetic counselling services are provided at hospitals, to advise disabled people, or people in whose families disability has occurred, on the chances of their children being born disabled. Says a former medical social worker, "there is quite a severe judgement against people who decide to bring potentially disabled children into the world." What would be preferable, she says, would be an approach which emphasises people making their own decisions.

Involuntary sterilisation

Or they go to your aging mother who is with you and they get her to fill in her name and signature on a form. They say, "We're just giving you a little injection." But this one contains an anaesthetic which puts you to sleep. When you wake up you realise that some kind of operation has been performed on you. No one even bothers to tell you that you have been sterilised.

For people who are severely mentally disabled there may be people who say that sterilisation is for the best. But, says Maria Rantho, "to just go on with sterilisation procedures and the like without actually going into the details about whether this is what is actually needed - I don't think this is in any way right. This person is a human being

and people have to respect that."

"They just tell you that they are doing an operation, what operation you are not told, and the next thing you are sterilised. And there you are, you fall in love, you get married, and you want to start a family, and the chances of you now starting a family are completely destroyed." Sometimes even the woman's parents aren't consulted.

In addition to making a thorough appraisal of whether sterilisation is advisable, and in the absence of a patient being able to give her own informed consent, the health worker should take care to ensure that the patient's parent or guardian, who would be required to give their approval to the operation, is informed about the nature of the operation which is being undertaken. In South Africa, where health worker and patient often speak different languages, this problem of communication may be an especially difficult one.

Looking forward

Over the recent period the outlook for disabled people has improved in certain respects. An important part of this is that disabled people have become more vocal and more militant in asserting their rights. On an international level an organisation, Disabled People International, now provides a link between disabled people from all parts of the world. In South Africa DPSA acts as an umbrella body for self-help groups.

One place where the public have increasingly been exposed to the reality of disablement is at the movies. Films like the Elephant Man, Children of a Lesser God, Rain Man, My Left Foot and Born on the Fourth of July, present the experience of disabled people in a way which makes this more tangible to people generally.

But a more positive climate for disabled people doesn't mean that things have really changed. There is still much that needs to be done.

Assertiveness

For the disabled person the battle is not only against the handicap imposed by one's disability, but also to escape from the cage which one is trapped in as a result of other people's assumptions and prejudices. "The skill of assertiveness is one which needs to be encouraged," says one woman who has done a lot of work with disabled people. "For many it is an uphill battle to break away from an attitude which says "there is nothing I can do.""

Assertiveness can be of value to disabled people not only on an individual level but also, through organisations like DPSA, in the political and public arena. Disabled people can be mobilised to confront others, the person on the street as well as political and other organisations, to become more attentive to their needs.

For disabled women the battle is an even harder one. Many people will see a disabled

women who asserts herself as having failed to accept her lot in life, as pushy, and as failing to acknowledge "reality". She may be accused of not knowing her place and of not being grateful for what others have done for her. As Maria Rantho says, to assert yourself, "You have to be a very strong person and you are definitely going to be very unpopular."

Health care workers

For health care workers part of the task is to confront their own prejudices and assumptions, as well as those of people around them, and to work towards providing disabled people with more effective assistance. Treating a patient holistically involves addressing their physical, psychological, social and spiritual needs. Health care workers should aspire to being agents of the liberation of disabled people rather than perpetrators of their oppression.

Educationists

For health educationists the challenge is to better prepare health care workers to recognise the humanity of disabled people. More broadly, health and other educationists, need to assist in the process whereby disabled people become fully integrated into our society.

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Glossary

Sex vs. Gender - **Sex** refers to the biological/physiological difference between men and women. **Gender** refers to the "male" and "female" roles which society assigns to men and women. These relate to, for example, their responsibilities in the home, the kinds of work which they do, and the kind of behaviour which is expected from them. Gender roles differ culturally from community to community. The expectations and definitions which they impose are oppressive to men and especially to women.

Reproductive labour vs. Productive Labour - work done in maintaining the household, providing food, and caring for members of the family or household. It is usually done by women who do not receive a wage for it. (Domestic workers are employed to do reproductive labour usually for a wage). Because the labour is "hidden" in the home, it goes by unaccounted for and unacknowledged. It is seen as "unproductive" labour and accorded a low status in society.

Reproductive labour must be seen in relation to productive labour which is done outside of the home, in return for some kind of wage income. Historically, men have mainly done productive labour. Women usually do almost all the reproductive labour and often/ usually do productive labour as well. In terms of the distinction that is being made here, work on factory production lines and in mines, as well as clerical and sales, or provision of professional services, is regarded as productive labour.

Women are said to perform a reproductive role in society in that they bear the children and do most of the reproductive labour. Feminists argue that men and women should carry equal responsibility for reproductive labour in the household.

TLVs - Threshold Limit Values. Refers to the quantity of a particular hazardous substance, (eg. lead, pesticides), that a worker can be exposed to without the substance damaging their health.

Maternal mortality - refers to the death of a woman during either pregnancy, childbirth, or 42 days thereafter.

AIDS - Acquired Immune Deficiency Syndrome. People get AIDS as a result of having HIV in their blood. They may only get AIDS as much as 10 years after they get HIV.

HIV - Human Immunodeficiency Virus. People get AIDS as a result of having HIV in their blood. HIV is mainly transmitted through:

- unprotected sexual intercourse (intercourse without a condom),
- via infected blood - in transfusions, and through the reuse of needles, syringes or other skin-piercing instruments,
- from an infected mother to her baby - before, during or after birth.

HIV-positivity - a person whose blood is tested and who is found to have HIV is said to be HIV-positive.

Safe-sex - the term is used to refer to sexual practices which lower ones risk of contracting HIV and other sexually transmitted diseases eg. having only one sexual partner, using condoms, non-penetrative sex. Celibacy is an option that people could also consider.

Sex worker - in this edition the word "sex worker" is used interchangeably with the word prostitute. Generally the term refers to anyone working in the "sex industry", that is, escorts, prostitutes, strippers, etc.