South Africa's Forgotten Children

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Much has been written on the health status of women and children in South Africa's rural areas. Yet very few have highlighted the plight of children with disabilities living in the rural areas of South Africa.

Prevention, Identification and Early Intervention

The majority of disabilities in rural areas are preventable. Ineffective immunisation programmes, poor health of pregnant mothers, lack of accessible delivery care (clinics do not operate on a 24 hour basis in rural areas), poor nutrition status of infants and lack of services, have led to a situation in which South Africa renders one of the poorest health services to children in developing countries. Impairments such as eye diseases or chronic ear infections often lead to permanent blindness or deafness. Measles, tetanus, polio and other preventable illnesses are common causes of disability in a country where organ transplants or triple by-pass surgery is an every day occurrence. Genetic research and counselling services are still a myth in the majority of rural areas, although slow in-roads are being made by a few initiatives. It is important that any counselling and research be done in consultation with local organisations of disabled people, and be coupled with direct service-delivery.

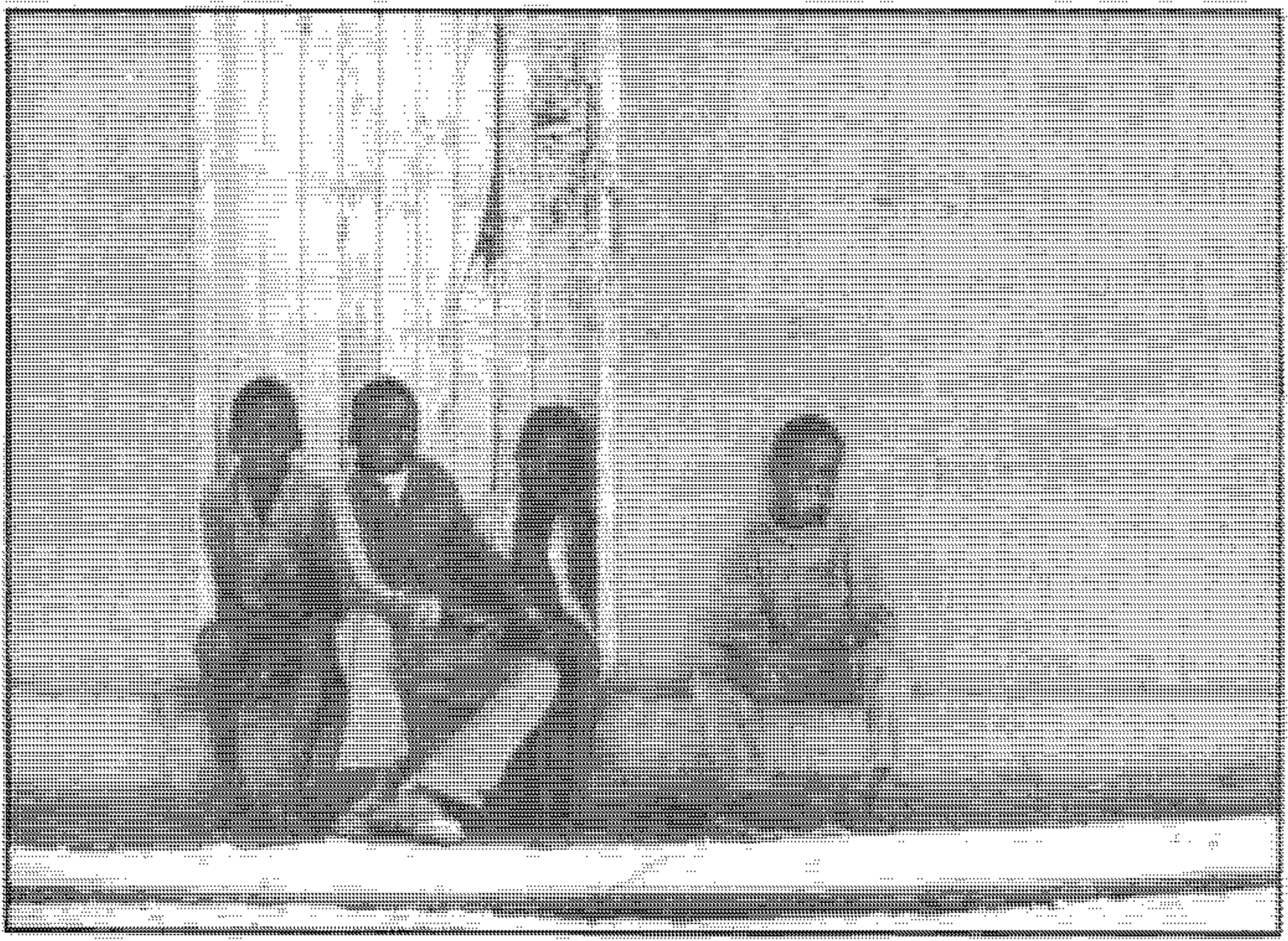
Early identification of and intervention among children at risk is vital to prevent disabilities from becoming handicaps. The disabled child has to learn to cope in a disabling world while experiencing the normal development phases of a child. Parents need to support the child in this process. The family needs to cope with the attitudes and barriers that society erect as defence mechanisms.

The primary health care system is overloaded and understaffed. Screening for children at risk is, therefore, very limited. Unless a disability is visible, little or no intervention is offered. 'Invisible' disabilities such as deafness often go undetected until the age of 2-3 years. As a consequence, untreated chronic ear infections, because of a lack of medication, leads to unnecessary disability. A well staffed, sufficiently financed and comprehensive rehabilitation and disability prevention policy would contribute tremendously towards prevention of disability at a primary level. This would include orientation and training of PHC staff at all levels in disability prevention, effective referral systems and affordable intervention therapy through community based rehabilitation programmes.

Constraints on Early Intervention

The minority of disabled children that are referred to hospital by the local clinics are seen by a medical practitioner who follows up on the medical aspects only. The severe lack of para-medical staff in rural areas delays therapeutic, educational and functional intervention until school going age. The shortage of para-medical staff also prevents effective early intervention because of a lack of time, inappropriate training of staff to cope with conditions pertaining in rural areas, and poverty of parents. The perception that only "professionals" have the knowledge and skill to intervene also adversely affects early intervention programmes.

The only successful early identification programmes are usually research programmes focused on the incidence of disability. These are often linked to



The lack of staff in rural areas prevents therapeutic, educational and functional intervention before school-going age. ***Photo: Afrapix***

post-graduate studies. These studies are seldom coupled with service provision, with the result that thousands of disabled children are identified, labelled and then forgotten. The only ones who benefit are the graduates who can boast a new title and salary increments. Deciding on priorities in research should be done in direct consultation with organisations of disabled people. It should lead to empowerment and skills transfer to the communities affected by research. Parents of disabled children have reached a point of refusing to participate in any professional research, which has brought them little more than unfulfilled expectations and broken promises.

The National Welfare Council has neglected rural areas in their scope of work in the past. It is only recently that it has started investigating ways and means of rendering services to children in rural areas. Concern, however, exists over how appropriate this intervention will be if based on urban experiences. It has to be pointed out that a tremendous industry has been created on the backs of disabled people and children. This can only be justified if the benefits to consumers of services exceed those of the benefits to the service providers. Mothers of disabled children in a rural area of the northern Transvaal recently pointed out that they can acquire 15 to 20 wheelchairs for the price of a social worker over the period of a year. The actual waiting list for wheelchairs was longer than this.

Parents Respond: Disabled Children Action Group

The Disabled Children Action Group (DICAG) was formed by parents of disabled children. They have embarked on an intensive programme to change the perceptions, laws and discriminatory practices clouding the development and advancement of children with disabilities. The programme concentrates on empowering the parents of children with disabilities, to instill in them the knowledge and will to transform society in a way which accommodates them. Parents have mobilised and are establishing day care centres all over the country.

DICAG has established seven regions and is governed by a council. This council is made up by two representatives from all regions of DICAG. An executive takes care of the day to day running of the movement.

The Rural Disability Action Group (RURACT)

RURACT seeks to contribute to the equalisation of opportunities for disabled persons from rural areas, through the facilitation of effective, participatory and empowering service provision.

RURACT was formed in 1986 by people working with disabled people in extremely isolated conditions in the rural areas. In 1989 disabled people living in rural areas started organising themselves with the assistance of RURACT members. RURACT has achieved something unique by creating a forum where disabled people, parents of children with disabilities and services providers can communicate freely on issues affecting the lives of disabled adults and children living in rural areas.

The empowerment and mobilisation of disabled people and parents of disabled children have been an important part in the process of development. This has enabled disabled people to discuss issues affecting their lives and to organise around theses issues for the first time. It has also enabled them to participate much more effectively in forums in which they represent themselves.

This has taken place in line with the United Nations document, *The World Programme of Action Concerning Disabled Persons*.. The purpose of this programme is, "to promote effective measures for prevention of disability, rehabilitation and realisation of the goals of full participation of disabled persons in social life and development, and of equality".

Community Based Rehabilitation (CBR)

RURACT has been actively campaigning for the recognition of CBR as an alternative rehabilitation model to the traditional institution based model since the mid-eighties.

CBR is a process of facilitating change in society through the transfer of skills to the community-at-large that will bring about equal opportunities and recognition of the rights of people with disabilities. It enables people with disabilities to access resources of their choice in their communities.

Both the Department of National Health and Population Development and the progressive health sector have adopted the CBR approach as the most viable rehabilitation model for South Africa. This response comes as a direct result of RURACT's relentless lobbying for the acceptance of CBR. Their commitment is, however, not backed by sufficient allocation of resources. The CBR worker training programmes at Alex Health Centre and Tintswalo Hospital, for example, still rely on private funding. Very few posts exist for community based rehabilitation workers, including categories, such as community speech and hearing therapists, community workers, mobility instructors, etc. Slow progress is, however, being made through local community lobbying as a result of an increased community awareness of disability, and the rapid growth of the disability rights movement in rural communities.

Barriers in rural areas. Disability is a socio-economic problem, not a health and welfare problem. ***Photo: Ismail Vawda***

It is important to note that CBR cannot exist in isolation. It has to be backed up by appropriate institution based services, and it has to be an integral part of an overall rehabilitation policy, covering the health, welfare, education and employment sector. The establishment of a national health forum will facilitate at least some progress in this field.

The role of CBR within the PHC system is being debated and investigated by RURACT and various other players at present. Some of the concerns that have been expressed is the selective way PHC has been implemented in South Africa. The main causes of ill-health and disability in rural areas are still caused by lack of sufficient clean water, lack of land, sewerage systems, lack of infrastructure, poor education etc, despite extensive PHC programmes in these areas. One therefore finds that even 'model programmes' severely lack vision of comprehensive PHC.

Disability in rural areas is not a health and welfare problem. It is a socio-economic and development issue. The mobilisation of parents has pressurised policy-makers and service providers to address the crisis of disabled children, especially those living in the rural areas of South Africa, in a holistic way that recognises that all children have the same rights.

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