

Grants for Disabled Children

A Desperate Need

Vuyo Mahlali

The gross neglect and marginalisation of people with disabilities, especially children, is in dire need of redress in this country. People's initiatives and creativity, some of which are as a result of survival or coping mechanisms to address the plight of these children, cannot be sustained if not adequately supported by the government and the private sector. The compounding effect of racist laws and insensitive social legislation, as well as the unwillingness of the authorities to promulgate or enforce legislation has devastated a large proportion of potentially active members of society.

Parents of children with disabilities see grants and subsidies contributing to the survival, protection and development of a child with a disability. In workshops run nationally with the majority of participants from rural areas, parents and people with disabilities shared experiences which show that:

Firstly, a child with a disability cannot have access to centralised health care facilities without financial assistance. For example, a mother in Tyolomnqa, a Ciskei village, told a story about her 14 year old daughter who had an appointment at East London's Frere Hospital, approximately 60 km away. This child has a mental disability. The mother, with the little money she had, arranged with a taxi driver to transport the child to and from the hospital. The mother could not accompany the child for lack of money. Unfortunately, the taxi driver could not locate the child on his way back. She was found a few days later, after having been sexually molested by strangers.

Secondly, parents are compelled by lack of facilities to stay at home and look after their disabled children (This not only affects the child but the whole family. Special schools are few and inaccessible to most families. Reportedly, only 20% of African children were in special schools in 1987. Arranging transport and assessment for placement in schools is costly, especially in rural areas).

Where parents started their own home-based centres to facilitate normal development of their disabled children, they found no support for their initiative from the government.

Single Care Grants

Single Care Groups (SCG's) are paid in terms of the Mental Health Act of 1973 for children with severe or profound intellectual handicap. Severe handicap, according to the Potgieter Committee Report, 1988, refers to children with "an IQ of between 30 and 50, and profound handicap indicates those with an IQ at 30 or lower, who are unable to benefit from general, specialised or special education or training and who are usually cared for in a care and rehabilitation centre". Unlike disability grants for adults received for all disabilities and paid as social grants under the Social Pensions Act, SCG's are paid to those who "incur expenses for medical treatment" among those eligible for the SCG. The Committee headed by magistrate de Meyer recommended that the grants be paid out in terms of the Social Assistance Act, rather than the Mental Health Act. It also recommended that the involvement of the Department of Justice be dispensed with, and called for a simplified assessment procedure and uniform criteria of payment for all races. There is, however, no recommendation for the extension of this service to all disabled. As a result, parents are still not satisfied and are unclear about what steps will be taken to address the committee's recommendations and to deal with concerns that have not been addressed by De Meyer.

Subsidies for special day care centres

As a result of these problems, informal home-based centres are mushrooming countrywide. Yet no measures are being taken by the government to enhance the initiative taken by parents. This is shown by the recent commission of enquiry on special day care centres headed by Van Niekerk which did not address the issue at all. Recently representatives of Disabled Children's Action Group (DICAG) in the Western Cape met the Cape Provincial Administration to discuss subsidisation of DICAG centres. The meeting was fruitful as both sides explained their situations and policies clearly. This, however, did not solve the problem. A number of obstacles stand in the way. One of these is the fact that groups need to be affiliated to a registered welfare organisation like the Cape Mental Health or the Association for Physically Disabled to qualify for a subsidy. Another obstacle is the requirement that children be severely or profoundly mentally disabled. If a group applies for a creche subsidy, the children must be of a preschool age. Parent's initiatives are also required to have clear structures.

These posed problems for parents as the centres they started were interim



Only 261 black mothers in the whole of South Africa receive single care grants. Photo: Atrapix

structures to accommodate all disabled children on waiting list for formal schools. Some of them have even organised monthly visits from doctors and therapists to assess children and refer them to relevant centres and schools. These centres accommodate all disabilities, with the average age of children between 3 to 14 years. They are in 'rondavels' in villages, in churches, community halls, shacks, containers and backyards, etc.

When asked why they do not want to affiliate to welfare organisations mothers said "we started these for a purpose because our children were on these welfare waiting lists for years, if we left them at home and looked for work they were neglected and raped, sometimes there will be space for a child in a centre but you will be told that their transport does not enter some squatter areas like Crossroads. You wait and wait by the time they take the child they say he/she is too old or too stupid. Once they take over they find other disabilities but they do not give them any option. We are here to help all the disabled children and we have therapists, rehab workers and doctors who show us how to group the children and what to do with them. The government has failed and we are now doing their job, they (government) must help us. We are prepared to do the job."

These voices need to be heard, as the solution will not only come from a government that will deliver, but a government that listens first to the voices and

together with them find a solution.

A frustration for black mothers is the fact that the SCG is not available to the majority, only 261 children in South Africa receive the grant and 'homelands' like Gazankulu, Lebowa, KaNgwane do not offer SCG.

The confusion and red tape one has to go through is an additional problem. Part of this confusion arises from a mistake made in the manual made by magistrates which states that grants are paid out from age six to sixteen instead of three to sixteen. When this was questioned, magistrates were given the mandate to "use their own discretion". This confusion was also witnessed from the lack of uniformity in amounts paid to children. When black children were supposed to receive R150 at the beginning of 1992, some received R80, R100, R130, and R150 respectively.

In a workshop held in KwaZulu, a government representative explained to parents the procedure for applications. This was stated as follows: "First the parent sees the problem in the child, and takes the child to the doctor. The doctor confirms the disability. The parent then goes to the social worker who applies for the SCG. The parent then goes to the magistrate, who sends it back to the social



Women already play the role of care-givers. Why isn't the state assisting them? Photo: UNICEF

worker to assess the home situation. The social worker sends the report to the attorney general in Pietermaritzburg. The attorney general processes the application and sends it back to Ulundi (KwaZulu). Ulundi ensures that all the correct documents are there, in order, and then advise the local magistrate to pay grant out. The magistrate decides when and how payment starts. The health department of Ulundi is responsible for processing grants."

This means that in areas where there are no social workers, children cannot receive grants. In general, it takes almost a year and even longer for grants to be processed, depending on the urgency of the case and the extent to which the social worker pushes.

Parents of disabled children on 26 October 1992 marched to the CPA to hand over a memorandum with demands to correct the above issues. They then sent representatives in January 1993 to a government welfare Interdepartmental Consultative Committee in Pretoria to discuss their demands. These included the call for government recognition of the parents' movement, DICAG, an affiliate of Disabled People of South Africa (DPSA) which aims to protect and promote the rights of disabled children. The representatives demanded that no changes should occur without consultation with parents. Unfortunately, the government did not honour this request. The appointed commission of enquiry after the parents' march and calls from the mental health societies to address the issues, published their findings and recommendations without consultation with DICAG. This raises concern especially when there are new initiatives to facilitate consumer participation in policy issues like the National Co-ordinating Committee on Disability which involves organisations for and of disabled people including the government.

Vuyo Mahlali is the national co-ordinator of the Disabled Children Action Group