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PERCEIVED NEEDS OF DISABILITY GRANT RECIPIENTS IN A SEMI-RURAL SOUTH AFRICAN AREA

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1. INTRODUCTION

In South Africa many persons with disabilities and their families rely on social assistance from the government (Mbeki, 1997). According to the White Paper for Social Welfare (1997) 8,7% of the 1995/96 consolidated national budget was allocated to the welfare budget, the largest proportion (88%) being utilised for social assistance. Of this, 24% was allocated to disability grants.

Persons with disabilities often approach social workers in the public sector for assistance in their application for a disability grant. Persons with disabilities who are unable to work owing to their disabilities may apply for such a grant by submitting the relevant documentation as stipulated by the Social Assistance Act (*Government Gazette* No. 59 of 1992), the Welfare Amendments Act (*Government Gazette* No. 106 of 1997) and the Regulation Gazette (*Government Gazette* No. R 417 of 1998). The grant is allocated on a sliding scale depending on the individual's income and assets.

The controversy about social assistance for persons with disabilities is substantial. Oliver (1996:76) suggests that many welfare states have failed persons with disabilities as "welfare provision has compounded rather than alleviated discrimination". In his opinion, persons with disabilities are forced to depend on welfare benefits in order to survive, as there are barriers to other forms of income, e.g. employment. In South Africa past policies have resulted in a similar situation of "passive income maintenance through grants" (*Government Gazette*, No. 1108 of 1997:9). The previous Minister of Welfare and Population Development (*Cape Times*, 4.12.1998) stated that disability grants had a de-motivating effect on persons with disabilities and made them dependent on welfare. It is commonly accepted that the current welfare system, and particularly the social assistance system, has led to abuse. The White Paper for Social Welfare therefore envisages re-registering beneficiaries and integrating this data with the National Social Grants Register in order to address this problem (*Government Gazette*, No. 1108 of 1197).

In South Africa employment opportunities are scarce and many citizens rely on social assistance for basic subsistence. Mbeki (1997) indicated that approximately 30% of those persons with disabilities who received a disability grant in 1993 often had to support entire families with the grant. Presently, the Department of Welfare plans a shift from social assistance "to financing social services which are linked to social assistance" (*Government Gazette* Notice 463 of 1999:19). It is crucial, however, that the envisaged services should be needs driven, and that persons with disabilities should be represented at all stages of planning, implementation and evaluation of these services.

Both the White Paper on an Integrated National Disability Strategy (Mbeki, 1997) and the Integrated Provincial Disability Strategy for the Western Cape (draft document, 1999) recommend that power should be shifted from the professional to persons with disabilities and their representative organisations. This recommendation was informed by the demands of persons with disabilities for protection and promotion of basic human rights and the right to make a choice which underlies true democracies. This notion is also reflected in Chapter 2 of South Africa's new Constitution, the Bill of Rights (*Government Gazette* No. 108 of 1996). The first two articles of the Disability Rights Charter of South Africa reinforce the demand of persons with disabilities for non-discrimination and self-representation (Disability Unit of Lawyers for Human Rights, 1993). Furthermore, South Africa, being a member state, is bound by the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. This international document acknowledges that a needs-driven, comprehensive approach is vital when addressing disability issues (Lindquist, 1995).

In the light of the above, one aim of the present study was to establish the needs of a defined group of persons with disabilities. Recipients of permanent disability grants should, by definition, be representative of a sub-section of the disabled community. It was hoped that insights gained from the study would be taken into account when future services were planned in, and possibly beyond, the geographical area of the study.

2. METHODS

The protocol was submitted to and approved by the Research Committee C of the Medical Faculty of the University of Stellenbosch. Stakeholders (organisations representing persons with disabilities, local and provincial governmental and non-governmental organisation) were informed of the proposed study and their comments were invited.

The study population consisted of persons with disabilities who collected their permanent disability grant at the Kleinmond Post Office in June 1999. A questionnaire was developed which aimed at establishing, amongst other things, demographic characteristics, a disability profile, caregiver utilisation and needs of the subjects.

The disability catalogue used to establish the disability profile of the study population consisted of seven disability categories. These were based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH), a World Health Organisation classification system (WHO, 1980).

The needs section of the questionnaire was developed after an extensive literature review and discussions with persons with disabilities and rehabilitation professionals. The three areas of interest also assessed in the study, included grantees' perceived needs regarding social services, health services and their community. This information was captured on five-point Lickert scales, which enabled the respondents to indicate the degree of importance they attached to their expressed needs, e.g. "very important" to "not important at all". By including an open-ended question respondents were also given an opportunity to voice needs that were not listed in the questionnaire.

A pilot study was conducted in the Botriver/Caledon area and the revised questionnaire was subsequently translated into Afrikaans. The main study took place in June/July 1999. The researcher visited all grantees in their homes, explained the aims of the study to them and/or their proxies and guaranteed confidentiality. Face-to-face interviews were conducted in respondents' home language, once written consent had been given. Hence only self-reported information regarding disabilities, caregiver utilisation and needs was captured. It can be argued that self-reporting or proxy-reporting may lead to bias, as the grantees and/or their proxies could have over-reported disability, dependence or needs in order to reinforce their dependence on social assistance. However, in view of the demands of persons with disabilities with respect to self-representation, an important aspect of the study was to establish the grantees' opinions about their disability experience. Subjects were at all times reassured that information given would be handled confidentially, thereby minimising the possibility of obsequiousness bias influencing the grantees' responses.

In order to assess repeatability of the questionnaire, four subjects were randomly selected and interviewed on a second occasion.

Data were analysed with the statistical software package Statistica.

3. RESULTS AND DISCUSSION

The response rate was 90% (29/32). This indicates that the study population was sufficiently represented to ensure internal validity of the study. When testing the reliability of the questionnaire by interviewing four randomly selected grantees for a second time, it was found that 96% of the overall responses were the same at both interviews. This suggests a strong likelihood that data were collected in a reliable manner. The main discrepancy appeared in the importance ratings of the Lickert scales utilised for the needs sections of the questionnaire. However, most of these discrepancies were small, for example "very important" rather than "important" might have been chosen at the second visit.

In 48% of cases (14/29) the grantees only were interviewed, while both the grantee and the proxy were interviewed in 24% (7/29) instances. Grantees thus contributed to most interviews, which ensured that their personal opinions and expressed needs were captured.

The demographic details and the disability profile are reported elsewhere (Frieg & Hendry, 2000) Consequently, these results are only briefly summarised. Grantees were mainly men between 18 and 64 years old (median age: 40 years). Most subjects were single (59% or 17/29), but the majority did not stay alone (93% or 27/29). More than half of the persons with disabilities utilised a caregiver to some extent (66% or 19/29).

It was of interest to note that most respondents had multiple disabilities (86% or 25/29), i.e. they reported problems with activities in more than one of the seven disability categories. This is in marked contrast to the disability figures of the most recent National Census (1996), in which only 4% (6 499/145 538) of persons with disabilities in the Western Cape reported more than one disability (www.statssa.gov.ac.za). It could therefore be hypothesised that only persons with extensive disabilities qualify for social assistance. A summary of the disability profile of the study group is displayed in Table 1.

TABLE 1
NUMBER OF CASES IN SPECIFIC DISABILITY CATEGORIES

Disability category	NUMBER OF CASES	PERCENTAGE OF CASES
Situational	24	82%
Communication	20	69%
Body disposition	18	62%
Behavioural	17	59%
Locomotor	16	55%
Dexterity	11	38%
Personal care	10	34%

As the literature indicates that the overriding demand of persons with disabilities is their right to self-representation in matters concerning them (Oliver, 1996; Disability Unit for Lawyers for Human Rights, 1993; Helander, 1993), all the results of the present study relating to grantees' needs are reported in this publication. Tables 2–4 are ranked in order of perceived importance of the questionnaire items to the grantees. Percentages (rounded off) are given in brackets.

TABLE 2
NEEDS WITH REGARDS TO SOCIAL SERVICES

	Very important	Important	Uncertain	Not important	Not at all important
Increase in amount of disability grant	22 (76%)	4 (14%)	3 (10%)	0 (0%)	0 (0%)
Groups that provide support for your family	13 (45%)	6 (21%)	1 (3%)	0 (0%)	9 (31%)
Groups that provide interaction with other disabled people	10 (35%)	7 (24%)	1 (3%)	2 (7%)	9 (31%)
Training to learn an occupation	10 (34%)	0 (0%)	2 (7%)	1 (3%)	16 (55%)
Visit of a social worker	8 (28%)	4 (14%)	2 (7%)	2 (7%)	13 (45%)
Help with setting up your own business	7 (24%)	1 (3%)	3 (10%)	3 (10%)	15 (52%)
Transport to collect your disability grant	6 (21%)	2 (7%)	1 (3%)	3 (10%)	17 (59%)
Groups that provide interaction with non disabled people	6 (21%)	5 (17%)	4 (14%)	1 (3%)	13 (45%)
Transport to reach recreational facilities	4 (14%)	2 (7%)	3 (10%)	1 (3%)	19 (66%)
Transport to do your shopping	3 (10%)	3 (10%)	1 (3%)	2 (7%)	20 (69%)
Home help	1 (3%)	0 (0%)	1 (3%)	2 (7%)	25 (86%)
The provision of a more accessible house	1 (3%)	0 (0%)	3 (10%)	5 (17%)	20 (69%)

The most important finding was that persons with disabilities in this study population found the amount paid as a disability grant to be insufficient. While disability advocates, notably Oliver (1996), argue that welfare provision increases dependency and excludes persons with disability from society, it is acknowledged that in South Africa many of their families depend heavily on this financial support (Mbeki, 1997). Even when the maximum amount is paid, a disability grant is still below the household subsistence level (Mbeki, 1997).

In a previous study many persons with disabilities in South Africa were found to be economically inactive (Schneider *et al.*, 1999). In the present study this finding is further supported, as it was established that 93% (27/29) of the grantees were unemployed, thus justifying the strongly expressed need of the grantees for an increase in the amount of the disability grant. A number of respondents also indicated that they would appreciate a visit by a social worker, possibly further reflecting a desire to have their economic hardship addressed.

In view of the high unemployment rate found in this study population, it was surprising to find that the majority (55% or 16/29) felt it was not important to receive training to learn an occupation or to be helped to set up a business. This could possibly be linked to the fact that 48% (14/29) of the grantees, when indicating disabilities in the behavioural disability category, reported that they found it difficult to learn a new skill. This relationship was, however, not further investigated. It could also be possible that respondents were concerned about jeopardising their disability grant should they earn money. Some respondents did, however, find it very important to receive training (34% or 10/29) or help with setting up a business (24% or 7/29). Their opinions should therefore be considered when planning employment generating initiatives.

Support groups for family members and groups that provide interaction with other disabled persons were considered to be important or very important for the majority of the grantees (66% or 19/29 and 59% or 17/29 respectively). Addressing this need could be initiated by the local authorities as part of service delivery.

With regard to social services, 17% (5/29) responded that they had additional needs not listed on the questionnaire, including improved continuity of social service delivery, free telephone services for persons with visual disabilities and an increase of the amount of the "grant-in-aid" for caregivers.

TABLE 3
NEEDS WITH REGARD TO HEALTH SERVICES

	Very important	**Im portant**	**Un certain**	**Not important**	**Not at all important**
Clinic closer to your home	15 (52%)	3 (10%)	0 (0%)	3 (10%)	8 (28%)
Transport to the clinic	11 (38%)	5 (17%)	0 (0%)	5 (17%)	8 (28%)
The provision of assistive devices	7 (24%)	1 (3%)	0 (0%)	0 (0%)	21 (72%)
Visit of the district sister	5 (17%)	6 (21%)	2 (7%)	5 (17%)	11 (38%)
Somebody to help you improve your physical skills	4 (14%)	1 (3%)	2 (7%)	1 (3%)	21 (72%)
Visit of the orthopaedic aftercare sister	2 (7%)	0 (0%)	0 (0%)	1 (3%)	26 (90%)
Somebody to help you with some tasks on a daily basis	1 (3%)	2 (7%)	2 (7%)	3 (10%)	21 (72%)
Somebody to care for you permanently	0 (0%)	1 (3%)	1 (3%)	3 (10%)	24 (83%)
The provision of a wheelchair	0 (0%)	0 (0%)	0 (0%)	0 (0%)	29 (100%)

At the time of the study the Kleinmond authorities were planning a community centre, including a clinic. They may be well advised of the grantees' opinion that the present clinic was viewed as being too far away from where grantees lived. Respondents indicated that they needed a clinic closer to their homes and/or the provision of transport to the clinic.

The fact that very few people expressed a need for permanent care or help with some tasks on a daily basis did not necessarily reflect that they did not require help, but possibly that health and social services were not considered to be the providers of that assistance. As 66% (19/29) of the grantees in this study population utilised caregivers to some extent, these findings may support the notion of the Joint Position Paper on Community-based Rehabilitation that the families and immediate communities of persons with disabilities are the greatest asset in supporting persons with disabilities (ILO, UNESCO, WHO, 1994).

Most other aspects on the questionnaire regarding health services were considered to be unimportant by the grantees. This may be explained by the fact that most of these aspects are usually more applicable to persons with locomotor disabilities, of which there were only 55% (16/29) in the present study.

In the open-ended question inviting respondents to express needs not listed in the questionnaire, grantees indicated that some health services should be more readily available to them: psychiatrists and psychologists (3 grantees), eye specialists (2 grantees), state-employed medical practitioners

(2 grantees) and dentists (1 grantee). It can be argued that these are services that are not sufficiently available to South Africans living in semi-rural areas.

TABLE 4
NEEDS WITH REGARD TO THE KLEINMOND COMMUNITY

	Very important	Im-portant	Un-certain	Not important	Not at all important
Raising awareness of disability in your community	20 (69%)	3 (10%)	2 (7%)	3 (10%)	1 (3%)
Recreational facilities for disabled people	14 (49%)	4 (14%)	2 (7%)	3 (10%)	6 (21%)
Self help groups for disabled people	13 (45%)	4 (14%)	2 (7%)	3 (10%)	7 (24%)
Accessible public transport	6 (21%)	2 (7%)	1 (3%)	2 (7%)	18 (62%)
Home help volunteers	5 (17%)	3 (10%)	2 (7%)	3 (10%)	16 (55%)
Accessible pavements	4 (14%)	4 (14%)	1 (3%)	3 (10%)	17 (59%)
Accessible buildings	3 (10%)	2 (7%)	2 (7%)	2 (7%)	20 (69%)

Most participants (20/29 or 69%) regarded raising awareness of disability in the community as very important. Only one person (3% or 1/29) found this aspect totally unimportant. Helander (1993:216) proposes strengthening "all efforts aimed at sensitising the public and making it more aware of the abilities of disabled people" as one of six priorities for programmes concerning persons with disabilities in developing countries. This is supported by the White Paper for Social Welfare (*Government Gazette*, Notice 1108 of 1997). This document identifies raising public awareness as one of the key strategy guidelines. Mbeki (1997) also suggests embarking on public education programmes with the aim of increasing public awareness regarding needs and rights of persons with disabilities in order to change societal attitudes. The persons with disabilities in this study also clearly considered this a very important aspect.

Opinions of the subjects diverged on the issues of recreational facilities and self-help groups for persons with disabilities. The majority found these to be either very important or important and one person reported that there was a need for recreational facilities for the youth of the town. However, a considerable number of grantees did not attach any importance to these aspects. This is contradictory to the findings previously reported that grantees were in need of family support groups and groups that provide interaction with other persons with disabilities.

The questionnaire, which was based on the census figures on disability and the researcher's experience as a physiotherapist, may have been biased towards locomotor disability. This is highlighted by the fact that very few persons with disabilities found the issue of accessibility a problem and did not express needs in this regard. Personal observations made while conducting the study revealed that buildings, pavements and transport were inaccessible to persons with locomotor disability, but this was clearly not a major need of the grantees in the present study.

In concluding the discussion on the findings from the sections of the questionnaire dealing with perceived needs of persons with disabilities and the use of the Lickert scales, it must be noted that the category "uncertain" was seldom utilised. The literature suggests that people tend to use this option when they do not want to commit themselves or do not understand the question (Polit & Hungler, 1983). This was not the case for this questionnaire and this study population. The response "uncertain" was never utilised by more than 10% (3/29) of the participants for each of the 28 questions. This indicated that all the grantees and their proxies had understood the questions sufficiently to be able to air their positive or negative opinions on 90% of the needs sections of the questionnaire.

4. CONCLUSION

A possible shortcoming of the present study was that it was initiated by the researcher rather than by the recipients of permanent disability grants. However, persons with disabilities were extensively consulted while the questionnaire was being developed and during the pilot study. Some common trends could be identified in terms of perceived needs of the study population.

While it is true that the restructuring of social welfare policies is one of the many pressing challenges of post-apartheid South Africa, it is unlikely that the most urgent need of this study population, i.e. an increase in the amount paid as disability grant, will be met in the short term. The White Paper on Social Welfare (*Government Gazette*, No. 1108 of 1997), which was drafted after widespread negotiations with many stakeholders, emphasises that welfare programmes should promote optimal social functioning, but that the system was founded on racial inequity, which resulted in social disintegration and consequent social problems. The document acknowledges that resources are limited and therefore people's expectations, including those of persons with disabilities, cannot fully be met in the short term. The demands on the state are enormous and human rights activists maintain that no citizen should be deprived of living above acceptable standards (National Human Rights Research and Advocacy Project, 1998).

Legislation and services must be needs driven. In order to plan and implement social and health services as proposed in various documents persons with disabilities should be involved in the discussions and represented at every level (Mbeki, 1997; *Government Gazettes*, No. 1108 of 1997; No. 463 of 1999; Welfare Update, 2000; Integrated Provincial Disability Strategy for the Western Cape, 1999). It is therefore hoped that the needs, as expressed by a sub-section of the community of persons with disabilities, will further inform service delivery in the geographical area in which the study was conducted. This holds true especially with regard to the new community centre in Kleinmond, which is currently being built in an area which is physically closer to where the majority of the grantees reside.

This study also supports the view that the community, including persons with disabilities, local governmental and non-governmental organisations should initiate campaigns to raise awareness of disability in the community and promote support-group activities for persons with disabilities and/or their families. These findings therefore, further reinforce government's recommendation to engage in community-based rehabilitation strategies within a primary health care approach.

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