

**PREVALENCE OF DISABILITY IN A PERI-URBAN  
INFORMAL SETTLEMENT IN SOUTH AFRICA**

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# PREVALENCE OF DISABILITY IN A PERI-URBAN INFORMAL SETTLEMENT IN SOUTH AFRICA

## **ABSTRACT**

The aim of the study was to determine the prevalence of disability in the Vlakfontein community, to give the existing health service an indication of the number and identity of the people with disabilities and the extent and nature of the services required. A total of 1007 residents were screened for disability by local community health workers using a structured interview schedule. Substance abuse and depression constituted the highest rates of reported disability which contributed to a high overall reported disability rate. Disability and gender specific rates are given and then compared to those found in other South African surveys and the implications of the results are discussed.

## **INTRODUCTION**

Vlakfontein is one of a number of peri-urban informal settlements situated near Grasmere, to the south of Johannesburg and Soweto. The first residents erected shacks there early in the 1980's, and it now has a population of about 3600 people living in eight sections of the settlement, named alphabetically from A to H. According to recent study entitled "The Roots of Homelessness"<sup>6</sup> only 55% of the adult population of Vlakfontein had some form of employment. Vlakfontein has an organised leadership and a number of small shops, churches, taverns, traditional healers and a crèche. The water supply consists of an opened manhole to a mains pipe about 800m from the northern periphery. There is no school.

The clinic, funded by non-governmental organisations began in 1988, and is the only easily accessible health service. It is staffed on three days per week by seven community health workers (CHWs), a doctor and three trained sisters. The present role of the Vlakfontein CHWs is similar to the role of CHWs in other peri-urban health projects,<sup>11</sup> namely to share health knowledge, to help prevent illness, to treat minor sicknesses, to refer and to assist community development. There is no specific emphasis on disability or rehabilitation in their training or daily work. The nearest formal rehabilitation services exist at the Baragwanath, Ntalspruit and Sebokeng hospitals, all over 15km away.

A number of disability prevalence studies have been carried out in South Africa since 1980, some of which are still in print. The studies use interview schedules based on the World Health Organisation (WHO) screening questionnaire on disability<sup>9</sup> and the International Classification of Impairment, Disability and Handicap (ICIDH) of 1980<sup>14</sup>. Most of the studies gather data on a wide range of disabilities<sup>1,2,3,5</sup> and some have emphasised physical disability<sup>4,12</sup>. There is a variation in disability prevalence rates quoted by the various studies ranging from crude disablement prevalence rates of 3.9% in Mitchell's Plain<sup>1</sup> and 4.57% in Gazankulu<sup>3</sup>,

to a rate of 12.7% quoted in the 1986 Year of the Disabled Persons Report<sup>7</sup>.

## **DEFINITIONS**

The different aspects of disablement namely disability, impairment and handicap will be used according to the ICIDH definition. Impairment is any loss or abnormality of psychological, physiological or anatomical function, disability is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being and handicap is a disadvantage that limits or prevents the fulfilment of a role that is normal for a given individual<sup>14</sup>.

## **METHOD**

### **Study design**

A descriptive study in two phases, using a structured interview schedule, was done over a period of six weeks in July and August 1991. The first phase was designed to gather demographic information and to screen the community for disability whereas the second or follow up phase was intended to confirm the nature, cause and presence of a disability and ascertain the needs of the disabled people in Vlakfontein. Only the results of the first or screening phase will be reported and discussed in depth in this article; the follow up phase will be mentioned when it is necessary to illuminate aspects of the screening phase.

### **Pilot study**

The pilot study for the first phase was conducted by the community health workers in pairs, together with the occupational therapist or the development officer, in section B of Vlakfontein. This section was therefore not included in the main study. Thereafter, the interview schedule was modified and the mean number of residents per household was calculated. It was decided to map out the entire settlement before proceeding with the survey due to difficulties encountered in sampling systematically and because reports about the population size and total number of households were inconsistent.

## Study population and sample

The study population was defined as all people living in Vlakfontein at the time of the study, estimated to be 3576. The sampling unit was a household and the mapping exercise yielded a count of 894 dwellings. In phase I, a total number of 248 households (1007) people were systematically sampled from Vlakfontein sections A - H using the map as a basis. The number was chosen to ensure a 95% degree of confidence, based on an expected crude disability prevalence of rate of 3 - 5% (i.e. 2% variance) and confirmed number of 4,06 residents per household.

A key informant and a snowballing technique were introduced in conjunction with the quantitative research methods described above to allow for more community participation and case finding. (The community health workers were interested in interviewing disabled people already known to them and some people in the study sample knew of other disabled people and wished to refer them to the health service.) The results of this aspect of the survey will not be presented or discussed in this article.

## Measurement tools and method

The phase I structured interview schedule was based on the WHO Disability Screening Questionnaire<sup>9</sup>. Respondents were asked to report basic demographic information as well as difficulties experienced with seeing, hearing, speaking, moving, learning, behaving, feeling and the presents of fits. Two additional questions which related to problems with psychoactive substance use and depression were included because these were observed to be possible health problems in this community. The household head, or a responsible adult member, usually female, was the person interviewed in the screening phase.

The phase II interview schedules, based on the ICDH and the studies in Alexandra Township<sup>5</sup> and Gazankulu<sup>3</sup> contained questions related to ability to perform mobility, household, personal care and work related tasks as well as age of onset, cause and felt needs of the people.

The phase I and phase II interview schedules used for the key informant aspect of the survey were identical to those used for the main study sample but were colour coded to avoid confusion during analysis.

## Interviewers

The interviews for both phases were conducted by six community health workers employed at Vlakfontein clinic at the time. They were all respected female residents of Vlakfontein. Training for the survey extended over one week and included the ICDH, interview techniques, the ethics of surveys, role playing and exposure to self-help groups of disabled people, hospital based rehabilitation programmes and community rehabilitation workers. The community health workers were supported by an occupational therapist and a community development officer during the survey.

## RESULTS

The disability prevalence rates for all disabilities reported during the screening phase of the survey will be given.

In phase I residents of 248 homes (1007 people) were interviewed and of these 34.9% were proxy reported. 34.5% of those with reported disabilities were proxy reported.

Some characteristics of the sample population are worth noting, namely that 47.5% of the population were males and 52.5% were females (Table I). The median age of the population was 23.5 years and 26% fell below the age of 10 years. There was an unexpected decrease in numbers in the 10 - 19 year age group. Perhaps these children had been sent away to school. The educational pattern is distressing (Table II). In the school-going age groups (5 - 19 years), 37% had received no schooling at all. In the school-leaving age group (20-24 years), only 40% had completed primary school and only 2.7% had completed high school. The mean years in school for the study population was 3.4 (SD = 3.51).

		Male %	Female %	Total %	Total No.
Age	0-9	13.2	13.1	26.3	265
	10-19	6.2	8.8	15.0	151
	20-29	8.9	13.8	22.8	229
	30-39	7.9	7.8	15.6	157
	40-49	5.1	4.1	9.1	92
	50-59	4.1	2.8	6.9	69
	60+	2.1	2.2	4.3	43
<b>Total</b>		<b>47.4</b>	<b>52.6</b>	<b>100.0</b>	<b>1 006</b>

Note : Total does not equal 1 007 since the gender of one respondent was not recorded.

**Table I :** Population structure of sample

The mean number of years of residence in Vlakfontein was 2.9 (SD = 2.28). The number of people 60 years of age and over who received old age or disability pensions was 67.4%.

In the screening phase of the survey, 230 people or 228/1000 (22.8%) of the study population reported the presence of one or more disabilities (since some had more than one disability the actual number of disabilities reported was 319). It is important to note that this figure of 22.8% includes people who reported problems in the areas of drinking/drug use and depression. In many disability screening surveys psycho social problems are not screened at all. For comparison to other surveys, it is therefore worth noting that the rate of disability in Vlakfontein, if drinking/drug use is excluded drops to 148/1000 (14.8%) and further to 118/1000 (11.8%) if depression is excluded.

Age Group	None %	Some Primary %	Primary completed %	Secondary completed %	Total in age group
0-4	100.0	0.0	0.0	0.0	151
5-9	71.4	28.6	0.0	0.0	105
10-14	17.1	75.6	7.3	0.0	82
15-19	8.7	46.4	43.5	1.4	69
20-24	13.6	43.6	40.0	2.7	110
25-29	16.8	37.8	40.3	5.0	119
30+	30.1	43.7	25.6	0.5	359
<b>Total</b>	<b>39.1</b>	<b>37.6</b>	<b>22.1</b>	<b>1.2</b>	<b>995</b>

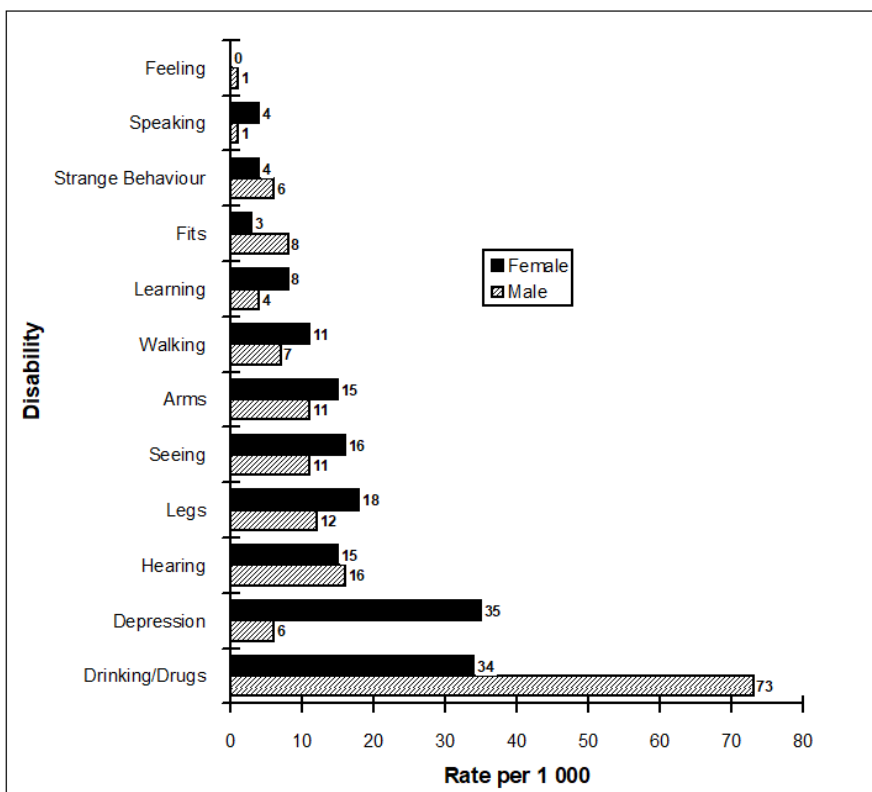
Note : Total number of people not equal to 1 007 since some ages and educational levels were not recorded during interviews.

**Table II : Level of education**

		No.	Rate	%
Disability	Drinking/Drugs	107	106	10.6
	Depression	40	40	4.0
	Hearing	31	31	3.1
	Legs	30	30	3.0
	Seeing	27	27	2.7
	Arms	26	26	2.6
	Walking	18	18	1.8
	Learning	13	13	1.3
	Fits	11	11	1.1
	Strange	10	10	1.0
	Speaking	5	5	0.5
	Feeling	1	1	0.1
<b>Total</b>	<b>319</b>	<b>317</b>	<b>31.7</b>	

Note : The rate of 317 is the rate of disabilities per 1 000 and not the rate of people with disabilities

**Table III : Reported overall disability rates per 1 000**



**Figure 1 : Reported gender specific disability prevalence rates per 1 000**

Thus the crude overall disability prevalence rate which includes reported communication disabilities, seeing disabilities, learning disabilities, strange behaviour, presence of fits, moving and feeling disabilities in Vlakfontein is 118/1000 or 11.8%.

The gender specific disability prevalence rates are illustrated in figure 1. In general, females appear to report more disability than males, except in the disability categories of substance abuse, fits, hearing and strange behaviour. In this study five times more females than males reportedly suffer from depression, with rates of 35/1000 for females and 5/1000 for males. With respect to the moving disabilities, once again more females reported disabilities as is seen by the rate of 11/1000 for females with walking disabilities and 7/1000 for males. This tendency is reflected in the reported rates for moving legs and moving arms as well. The overall crude reported disability prevalence rate for moving (i.e. people with physical disabilities) is 48/1000.

It is interesting to note that the reported prevalence of substance use problems was 73/1000 for males and therefore more than double the rate of 34/1000 for females. It is not surprising to see that together they constitute the most frequently reported disability in phase I (106/1000). Depression constitutes the second highest prevalence rate in the Vlakfontein community.

The most prevalent disabilities reported after drinking and depression were those of hearing (31/1000), seeing (27/1000), and moving of legs (30/1000), arms (26/1000) and walking (18/1000). The lowest rates were those of 12/1000 for learning disabilities, 11/1000 for fits, 10/100 for strange behaviour, 5/1000 for speaking and 1/1000 for sensory disability.

Table IV indicates the age specific disability rates for each reported disability. It should be noted that the sample sizes in some age groups are small and definite conclusions cannot be drawn.

## **DISCUSSION**

This study did not allow for the reported disability rates obtained in the screening phase to be confirmed by a professional examination, testing or a field diagnosis. Thus it is possible that these reported disability prevalence rates include a fair amount of impaired-not-disabled people as well.

The reported disability rates can firstly be compared with other reported (not confirmed) rates, and secondly with surveys where the level of training of the interviewers was similar. Thus our crude reported disability prevalence rate of 118/1000 (11.8%), excluding substance abuse and depression, is similar to a recent study in Mitchell's Plain<sup>1</sup> where the crude reported rate after screening by therapy assistants was 12.9%. It is noteworthy that the rate dropped to 39/1000 (3.9%) in Mitchell's

Plain when follow-up interviews were done by therapists and in a study in Gazankulu<sup>3</sup>, where both the screening and the follow-up interviews were done by a therapist, the crude disability rate was found to be 46/1000 (4.59%). Thus there appears to be a degree of over reporting of certain disabilities in Vlakfontein, which was to be expected, given the level of training of the interviewers. As was noted by the authors in Mitchell's Plain, "the fact that the error in reporting a problem at all was toward "false positives" is reassuring as one hopes that "false negatives" would be minimised"<sup>10</sup>.

The crude disability prevalence rate does not yield as much information as the disability specific rates do. The two problems of substance abuse, with a reported rate of 106/1000 and depression with reported a rate of 40/1000 have the effect of inflating the crude disability prevalence rate by a full 11% to nearly 23%. We are confident that our prevalence rate of substance abuse in Vlakfontein has been accurately reported since the health workers were known and trusted in this relatively small community. This is a screening survey therefore it should be borne in mind that this rate could possibly include people with minor psychiatric morbidity (impairment) as well as those with disabilities. A recent screening survey of depressive symptoms in black elderly people in Langa and Khayelitsha, yielded morbidity rates of 21% and 66% respectively<sup>8</sup>. In rural Gazankulu<sup>3</sup>, the rates for alcohol/drug use and depression were only found to be 5/1000 and 3/1000 respectively. Our initial perception that substance abuse and depression constitute a major health and socio-economic problem in Vlakfontein, appears to have been borne out by our results. They are indicators of the stress and poverty endured by peri-urban informal settlement dwellers and they highlight the need for resources to be allocated to development programmes and not only to medical or rehabilitation projects.

In studies where psychiatric disability ("strange behaviour") has been screened for, the reported prevalence rates differ. A rate of 3% disabled is quoted for Gazankulu<sup>3</sup> and a rate of 0.5% is quoted for Alexandra Township<sup>5</sup>. The reported rate of "strange behaviour" in Vlakfontein was 10/1000 (1.0%) but given the high reported prevalence of other impairments of mental health (depression and substance abuse) in Vlakfontein, one could perhaps conclude that this rate of 1% represents only the very obvious psychiatric disturbances, and there is likely to be a large pool of mental illness in the community. The study completed in Mitchell's Plain suggests that the initial reporting of a psychiatric problem is a good predictor of disability (Positive predictive value of 77%)<sup>10</sup>. A psychiatric epidemiological screening study by Parry has indicated that 16-21% of the general population suffers from minor psychiatric morbidity<sup>13</sup>.

DISABILITY	AGE							Total
	0-9	10-19	20-29	30-39	40-49	50-59	60+	
Learning	8	53	13	0	0	0	0	13
Fits	23	7	9	13	0	0	0	11
Hearing	23	33	17	25	43	43	116	31
Speaking	8	0	4	13	0	0	0	5
Seeing	11	7	35	19	22	72	116	27
Strange behaviour	0	13	9	6	11	58	0	10
Arms	8	13	13	38	22	101	93	26
Legs	4	7	9	32	65	145	116	30
Walking	8	0	4	19	11	87	116	18
Feeling	0	0	0	6	0	0	0	1
Drinking/drugs	0	7	140	185	217	188	186	102
Depression	4	26	61	64	76	43	23	40
<b>Total</b>	<b>94</b>	<b>166</b>	<b>314</b>	<b>420</b>	<b>467</b>	<b>739</b>	<b>767</b>	<b>313</b>

Note : Rates calculated using figures from population structure table (Table I).

**Table IV : Reported age specific disability prevalence rates per 1 000**

The reported prevalence rate of fits at 11/1000 (1.1%) is similar to rates found in Gelukspan<sup>4</sup> of 12/1000 (1.2%) and the 10/1000 (1%) prevalence rate accepted for South Africa in the Year of the Disabled Persons Report<sup>7</sup>. The ratio of males to females was higher as found in the literature. We believe this to be an accurate figure for Vlaktefontein since the health workers were experienced at identifying epilepsy during the course of their normal work at the clinic.

The prevalence rate of 27/1000 (2.7%) for reported seeing disability corresponds with a rate of 2.7% found in Alexandra Township<sup>5</sup>. We are of the opinion that this includes a substantial number of impaired-not-disabled people, as was the case in the Alexandra study.

The reported prevalence of hearing impairment and disability is high namely 31/1000 (3.1%) and compares closest with a rate of 40/1000 (4%) found in Gelukspan<sup>4</sup>. No field tests for hearing were done either in the screening or follow-up phase, therefore the presence and extent of impairment or hearing loss could not be verified. The Year of the Disabled Persons Report<sup>7</sup> proposes that "at least 3% of the total population are significantly hearing impaired".

The reported rate of learning disability (including mental retardation) of 13/1000 (1.3%) compares closely with a rate of 0.9% found in Alexandra Township<sup>5</sup> but is likely to be under reported in Vlaktefontein due to the generally low level of formal education present. In fact, the usefulness of prevalence figures for "learning disability" in an area where there is no school at all, is questionable!

The presence of physical and motor impairment and disability has been more extensively researched in South Africa. McLaren<sup>12</sup> found a crude prevalence rate of 12/1000 for upper limb disability in Kwazulu.

The crude rate of 26/1000 for reported upper limb disability in Vlaktefontein is probably over reported, including some reported impairment.

## **CONCLUSION**

### General usefulness of the study :

The crude overall rate of reported disability, although high, is comparable to that found in other areas in South Africa, where similar screening instruments and similarly trained interviewers were used. Psycho social impairments and disability constitute the largest reported problem and this has important implications in a country like South Africa where the rates of urbanisation, violence and unemployment are high and increasing.

The other individual disability rates are comparable to rates found elsewhere. Moving disability seems to have been over reported in this study in the screening phase as has been the experience in other studies. However it still constitutes a substantial proportion of the disabilities found.

It should be possible to generalise the prevalence data and needs to other similar informal settlements south of Johannesburg such as Weiler's Farm, Orange Farm, Sweetwaters and Fine Town. No rehabilitation services or data about the disabled people exists in any of these areas but the Grasmere Community Health Project which supported this study, offers regular clinic services and supports community health workers in a number of these areas.

The weakness of this study as a tool for measuring disability prevalence lies in its inability to confirm beyond doubt the reported rates or to adequately ascertain the severity of the disabilities for intervention purposes. It is felt that a field diagnosis would have facilitated confirmation of disability. In principle,

according to the ICIDH, disabilities are threshold phenomena and to establish the nature and existence of disability calls only for a judgement about whether a particular task can be performed or not<sup>14</sup>. Thus, it should be easy for field workers who do not have vast experience of disability to decide whether or not a disability exists. In practice we did not find this to be completely true. The questionnaires from the follow-up phase of this study, completed by the same CHWs who undertook the screening phase, were found not to be useful in confirming the existence of a disability as defined by the ICIDH.

Screening of disability performed by lay or auxiliary workers not trained in field diagnosis appears to lead to reported disability rates (which include impairment) of more than 100/1000 (10%). The "predictors of disability"<sup>1,10</sup> described in the Mitchell's Plain study have potential for simplifying disability screening fieldwork in the future, eliminating the need for large expensive follow-ups of all reported cases of disability.

#### Usefulness of the study to the Vlakfontein Community

The study has been useful in pinpointing the focus for the beginnings of a community based rehabilitation programme in an area where access to traditional rehabilitation services is poor.

The solutions to the problems of the disabled people in Vlakfontein lie both in community development and in development of the rehabilitation component of the health service. For instance, the substance abuse problems may be best approached through a community based awareness and actions, through improvement of environmental conditions which the communities leadership are lobbying for and through improvement of the educational facilities. The follow-up phase questionnaires are now being used by the clinic health service in Vlakfontein to identify clients for further contact leading to treatment, referral or inclusion in groups and other development projects. Women with reported depression have been identified and can be helped by gaining support through inclusion in the newly formed women's groups facilitated by the CHWs and the development officer. Mothers of disabled children can be assisted to form support and play groups using the crèche as a base. Some of the disabled people need referral for appliances or assistive devices and some need therapy. The potential for mobilising the adults into self-help/support groups is good, given that 78% of those with moving disabilities wanted to meet people with similar problems to find solutions.

The means to begin working in these directions exist in a small way. Firstly, the study served as a way of case finding since the community is small. Two sets of disabled people are known - those identified through systematic sampling and screening, and those concurrently identified through the process of key informant reporting and snowballing. Their homes are recorded on the map drawn.

Secondly, personnel resources are slowly developing. As a result of this study a community development officer was employed at Vlakfontein, an occupational therapist became involved for a limited period of time and thereafter a physiotherapist began following up clients on a few days per month.

The best long term option for development of rehabilitation services is to employ and train two community rehabilitation workers who would be supported by the clinic staff and the above mentioned people. Meanwhile the therapists and the development officer could begin working with the disabled people utilising the present CHWs. Health workers should be involved together with the community in lobbying for better environmental and other conditions such as an accessible, potable water supply and a school. The survey has yielded important information about the educational status of the community, the size of the population and the number of households.

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