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9 RESEARCH ARTICLE

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11 Disability and access to health care – a community based descriptive
12 study
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20 Abstract

21 Purpose: The World Disability Report highlighted the need for adequate access to health and
22 medical rehabilitation services for those with disability. Participants in a large community based
23 survey in a low-income area were asked questions relating to their use of health related
24 services. Method: Using random, cluster sampling a representative sample of 1083 households
25 in a deprived area of Cape Town were approached and 152 people with disability were
26 interviewed. Results: Those with disability were more likely to be male ($\chi^2 = 4.24, p = 0.03$) and
27 unemployed ($\chi^2 = 66.89, p > 0.001$) compared to those without disability. The percentages
28 reporting unmet needs were respectively: 54% for home-based care; 34.5% for assistive devices,
29 28.9% for medical rehabilitation services; and 2.5% for health services. Those over 65 years of
30 age were less likely to have had the medical rehabilitation that they required ($\chi^2 = 8.00,$
31 $p = 0.018$). There were fewer respondents with sensory and language disorders but these
32 groups reported proportionately more unmet needs. The main problems with accessing
33 services included inadequate finances (71%) and transport problems (72%). Conclusion: It is
34 recommended that all efforts be expended to extend appropriate rehabilitation services,
35 including home based-care and appliances to those identified as having disability, particularly
36 to those older than 65 years. In addition, the services need to be affordable and accessible in
37 terms of suitable transport, particularly in the light of the high unemployment rate and the
38 large number of respondents with mobility problems.

39 ► Implications for Rehabilitation

- 40 • People with disability may be the most in need of additional health related care and the least
41 able to access it.
- 42 • Transport and financial considerations were found to limit the ability to access appropriate
43 care.
- 44 • Rehabilitation and health services need to reach out through home-based care and
45 appropriate forms of rehabilitation delivery to ensure that those who are most in need of
46 care, such as the elderly and those with more neglected forms of disability, are provided with
47 the services that they require.

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50 Introduction

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52 The conceptual framework of the International Classification of
53 Functioning Disability and Health recognises the impact of the
54 environment on the ability of person with disabilities to mean-
55 ingfully participate in the life of the community and to benefit
56 from all services provided, including health and rehabilitation
57 services [1]. The World Disability Report (the Report) recognises
58 that people with disability need to be able to access appropriate
59 mainstream health care and rehabilitation to a greater extent than
60 people without disability [2]. Several reasons are suggested for

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this, including those related to their health condition, such as
secondary or co-morbid conditions, and greater vulnerability to
violence, unintended injury and age related conditions. In high-
income countries, those with disability account for a dispropor-
tionate amount of health care expenditure. In the US, for example,
De Jong et al. analyzed the 1996 Medical Expenditure Panel
Survey (MEPS) and concluded that individuals with disabilities
use more health care services than do other. They reported that
adults with functional problems accounted for one third of
physician visits, 62% of hospital days, and 46% of adult-related
health care expenditures [3]. Ironically, in many contexts, those
who are most in need might be the least able to access appropriate
health care, precisely due to the nature of their disability. The
Report indicates that the percentage of people with disability
unable to access required care is higher than for those without
disability in every age range, and higher in low income compared

133 to high-income countries [2]. Mobility limitations, compounded
134 by the lack of adequate transport facilities might make access to
135 health care exceedingly difficult. The obvious barriers to access
136 include architectural barriers, and appropriate enabling equip-
137 ment, such as lift or transferring devices, accessible scales,
138 examination tables and mammography machines [4] are often not
139 available. Attitudes of health professionals have also been
140 identified as a barrier to accessing health services [5].

141 In addition, the prevalence of the major categories of ill-health
142 and disability is greater among lower than higher socio-economic
143 groups as demonstrated by Ataguba et al. [6]. They state “South
144 Africa represents a classic example of the inverse care law; the
145 lowest socio-economic groups bear the largest burden of ill-health
146 but have the lowest level of health service utilisation and derive
147 the least benefits from service use” [6].

148 The aim of this article was to respond to the recommendations
149 made in the Report, specifically those pertaining to the need to
150 gather data on rehabilitation needs, and unmet needs, disaggre-
151 gated by sex, age and associated health condition [2]. This
152 entailed an examination of the factors that impact on the ability of
153 people with disability to access health care in a middle income
154 country, among those who have the least amount of financial
155 resources. It was hypothesised that a combination of functional
156 limitations and environmental factors would have the greatest
157 impact on access to services.

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159 Method

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161 Study design

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163 The study was nested within a larger survey on the prevalence and
164 epidemiology of disability. A descriptive cross-sectional house-
165 hold survey was conducted in an urban area in the Cape Town
166 Metropolitan area, which has one of the lowest scores in the
167 national Multiple Deprivation Index Survey [7] indicating
168 extreme deprivation. The inhabitants are mostly isiXhosa speak-
169 ing black Africans.

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171 Sample

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173 The sample size was calculated using Epi-Info StatCalc,
174 Version 6. In a population of 100 000, with an estimated
175 prevalence of disability of 5.2% [8], (95% Confidence Intervals
176 4.6–6.0%), the sample required was 2874 subjects. However, as
177 cluster sampling was used at the level of geographical area, a
178 design effect of 1.3 was used to allow for the similarities within
179 each cluster. The final sample size required was therefore 3640.
180 Anticipating that the average household consists of four
181 members, the required number of households to be visited was
182 a minimum of 910.

183 The proportion of free standing, semi-detached homes, flats
184 and informal settlements was determined using census data
185 relating to the suburb. Google Maps were used to identify the
186 sampling frame and ensure that those in back yard, formal and
187 informal housing were proportionally represented.

188 Using the aerial map of the area of the area, 14 informal
189 settlement areas, 21 formal housing areas and one formal housing
190 area in which back-yard dwellings were included were identified
191 and demarcated giving a total of 36 discrete geographical areas.
192 Each was then given a number and stratified random sampling
193 was performed using the Excel random number function to select
194 23 small geographical areas, such as street blocks. Within each of
195 these smaller areas, one of the four “corners” of the cluster or
196 block was chosen randomly and ten dwellings in each street were
197 identified on the map, starting from the second house to the left of
198 the street corner and then including every second house from this
point on until 10 houses were visited.

199 Randomised, stratified, cluster sampling was therefore utilized.
200 If for any reason, respondents in the identified household could
201 not be interviewed a further visit on an alternative time was
202 attempted before exclusion. Subjects included all adults and
203 children who were permanent residents in the household
204 identified. The most senior member present at the time of the
205 visit or the head of the household was asked to provide
206 information on all the other members.

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208 Instrumentation

209 The Washington Group on Disability Statistics Short Set of
210 Questions [9] was used to identify people with disability.
211 A demographic questionnaire was designed for the purpose of
212 this study. It consisted of three sections concerned with
213 demographic characteristics (e.g. age, education) social charac-
214 teristics (e.g. household composition) and biomedical character-
215 istics (e.g. duration of impairment, acute or chronic concomitant
216 illness).

217 Questions which related to service delivery included whether
218 the participants were aware of the different services, whether they
219 needed the services and whether they had received the services.
220 There was also a general question relating to problems with
221 accessing services. The questionnaire was translated into isiXhosa
222 and was piloted on a group of isiXhosa speaking people.

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224 Procedure

225 Ten enumerators were recruited and trained on how to conduct the
226 interview, and how to complete the questionnaire. A supervisor
227 was employed to manage the data collection process and to ensure
228 the accuracy of the data collected. The informant was interviewed
229 and completed the demographic questions and the screening
230 questionnaire for the whole sample. If he/she reported that there
231 was a member of the household with a disability, this person was
232 either immediately interviewed or an appointment was made to
233 return to the household. Disability was defined according to
234 Washington Group on Disability Statistics Screening Questions as
235 those reporting “A lot of difficulty” in at least one domain. The
236 people with disabilities then filled in the questionnaire which
237 related to nature of their disability and their access to services.
238 Proxy report was used when the person with disability was unable
239 to respond to the questions, either because of age or nature of the
240 disability.

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242 Data management and analysis

243 Descriptive statistics were used to present the various components
244 of disability. As medical rehabilitation is the focus of this article,
245 this was chosen as the variable to discriminate between those able
246 to access care and those in need who had not had intervention.
247 Three groups were identified, those not needing rehabilitation
248 (Not needed), those who needed and received rehabilitation
249 (Received) and those who needed but had not received rehabili-
250 tation (Not received). Chi-squared was used to test for association
251 between categorical variables such as gender and disability status
252 or access to medical rehabilitation.

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254 Ethical considerations

255 Ethical approval for the study was given by the Human Research
256 Ethics Committee of the University of Cape Town and informed
257 consent was obtained from all participants. In the case of minors
258 or disabled person who were not able to give legal consent,
259 written informed consent was obtained from the parent(s)/legal
260 guardian. People identified as being in need of rehabilitation were
261 informed about the relevant services in the area.
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Table 1. Number of respondents reporting difficulty on the different Washington Group Screening Items ($n = 151$).

	No difficulty	Some difficulty	A lot	Cannot do at all	Total
Seeing	91	43	14	3	151
%	60.3	28.5	9.3	2.0	100.0
Hearing	85	35	28	3	151
%	56.3	23.2	18.5	2.0	100.0
Walking	23	11	78	39	151
%	15.2	7.3	51.7	25.8	100.0
Remembering	37	55	43	16	151
%	24.5	36.4	28.5	10.6	100.0
Self-care	79	30	25	17	151
%	52.3	19.9	16.6	11.3	100.0
Communication	97	23	19	12	151
%	64.2	15.2	12.6	7.9	100.0

Results

A total of 1083 households were approached. There were 44 refusals and data were gathered from 1039 informants relating to 3464 family members. There were 179 (5.2%) people who were reported to have a lot of problems in or unable to do in response to one of the screening questions. Of these 151 people with disability were available for interview. The responses of these 151 form the primary data for this paper. The mean age was 46.5 years ($SD = 20.5$, range 4–87, 29 missing responses) which was significantly older than the community sample (29.4 years, $SD = 16.6$; $t = 12.2$, $p < 0.001$). The underlying causes of the disability were post-coded as being unintentional injury (31.1%), aging and chronic diseases of life style (27.8%), childhood infections and birth trauma (17.9%), infection (8.0%) and other causes/missing (15.2%).

Of those with disability, 45.5% were female, compared to 54.22% of the sample ($\chi^2 = 4.24$, $p = 0.039$), the majority were unemployed (89.7% of those between 18 and 65) compared to 49.5% of the sample ($\chi^2 = 66.89$, $p > 0.001$) and 75.5% were receiving some form of grant.

The majority of respondents reported problems in the area of Mobility (85%) with 77% reporting a lot of difficulties or cannot do at all in this area (Table 1). The next most common problem was remembering (75%) with 39% reporting a lot of difficulties or cannot do.

Access to services

Of those who reported being in need of services, the largest percentage reporting that these needs were not met were in the areas of medical rehabilitation (30%), assistive devices (34.5%) and home-based care (56.4%). In contrast, only 2.5% reported being in need of medical care and not having received it (Table 2).

The specific services that were most required (both met and unmet) included physiotherapy, medication, home based care and the provision of wheelchairs and improved transport (Table 3).

There was no difference in the proportion of males and females who had had access to medical rehabilitation ($\chi^2 = 3.669$, $Df = 2$, $p = 0.160$). Similarly, there was no difference in the mean ranking of income categories, ($Z = 0.584$, $Df = 2$, $p = 0.558$), although those Not receiving had the lowest mean rank. Age did make a difference to access and the elderly (over 65 years of age) were less able to access treatment, with more than 50% of those needing not having received treatment ($\chi^2 8.00$, $df = 2$, $p = 0.081$; Table 4). People who reported hearing problems had the largest proportion of respondents who had needed but not received rehabilitation (52%). Those who had a disability secondary to infection were the least likely to have received needed

Table 2. Number of people with disability reporting services required and obtained ($n = 151$).

	Aware		Needed		Received		% Needing that did not receive
	Count	%	Count	%	Count	%	
Home Based Care							56.4
Yes	117	77.5	55	36.4	24	15.9	
No	31	20.5	83	55.0	113	74.8	
Missing	3	2.0	13	8.6	14	9.3	
Assistive devices							34.5
Yes	117	77.5	110	72.8	72	47.7	
No	27	17.9	30	19.9	70	46.4	
Missing	7	4.6	11	7.3	9	6.0	
Medical Rehabilitation							28.9
Yes	115	76.2	114	75.6	81	53.6	
No	30	19.9	26	17.2	68	45.0	
Missing	6	4.0	11	7.3	2	1.3	
Disability Counselling							17.6
Yes	118	78.1	108	71.5	89	58.9	
No	25	16.6	30	19.9	56	37.1	
Missing	8	5.3	13	8.6	6	4.0	
Welfare Services							12.2
Yes	134	88.7	123	81.5	108	71.5	
No	5	3.3	16	10.6	37	24.5	
Missing	12	7.9	12	7.9	6	4.0	
Health Services							2.5
Yes	120	79.5	122	80.8	119	78.8	
No	18	11.9	17	11.3	30	19.9	
Missing	13	8.6	12	7.9	2	1.3	

Table 3. Specific services required (met and unmet needs; $n = 121$, 30 missing, multiple responses).

	Count	Percent
Physiotherapy	25	16.6
Medication	22	12.6
Home based care	17	11.3
Wheelchair	13	6.0
Transport	13	5.3
Special school	10	6.0
Job placement	7	2.6
Walking aid	6	2.6
Spectacles	6	2.6
Disability grant	6	2.0
Hearing aid	4	2.6
Surgery	3	2.0
Prosthesis	2	1.3
Home for the elderly	2	1.3
Sports group	2	1.3
Occupational Therapy	1	0.7
HIV support group	1	0.7
Toilet	1	0.7
Computer	1	0.7
Support group for rape victims	1	0.7
Better access to health services – no queues	1	0.7
Missing	30	19.9

rehabilitation (42%) followed by those who had a chronic disease of life style (38%). Satisfaction with transport did not emerge as being associated with accessing needed rehabilitation services.

Problems with accessing services

Most of the respondents reported that they were unable to pay for services (70.9%) and that services were too far and they had no transport (72.2%). Other reasons for not accessing services were that they were not helping any longer (37.1%) that the respondents had reached the level of functioning that they had set

Table 4. Characteristics of those who did not need rehabilitation, those who needed it and received care and those who needed services but did not receive them.

	Not needed	Received	Not received	Total	% Needing that did not receive	Chi-sq (<i>p</i>)
Youth and adults	24	68	31	123		8.00 (0.018)
%	19.5	55.3	25.2		31.3	
Elderly (Over 65 years)	2	11	14	27		
%	7.41	40.74	51.85		56.0	
Missing				2		
Functional limitation (multiple responses)						
Seeing	3	8	6	17		
%	17.6	47.1	35.3		42.9	
Hearing	4	13	14	31		
%	12.9	41.9	45.2		51.9	
Walking	16	67	34	117		
%	13.7	57.3	29.1		33.7	
Remembering	9	34	16	59		
%	15.3	57.6	27.1		32.0	
Self care	7	21	14	42		
%	16.7	50.0	33.3		40.0	
Communication	4	15	12	31		
%	12.90	48.39	38.71		44.4	
Underlying cause (most common)						
Infectious	0	7	5	12		
%	0.0	58.3	41.7		41.7	
Maternal and child	8	14	5	27		
%	29.6	51.9	18.5		26.3	
Chronic diseases of lifestyle	8	21	13	42		
%	19.0	50.0	31.0		38.2	
Unintentional Injury	9	27	11	47		
%	19.1	57.4	23.4		28.9	
Other				33		
Total						
Satisfaction with transport						
Satisfied	13	63	33	109	34.4	1.09 (0.30)
%	11.9	57.8	30.3			
Dissatisfied	6	13	11	30	45.8	
%	20.0	43.3	36.7			
Missing				12		

as the goal of intervention and that services were no longer available (47.7%). Communication or a language barrier was reported as a problem with accessing services by 48.3% and 67.5% said that they were not satisfied with services. "Other" problems, reported by one or two respondents included poor staff attitudes and disrespect and the long waiting time for attention.

Discussion and conclusions

People with disabilities appear to have difficulty accessing medical rehabilitation and home care services. The sample is likely to be representative of those who dwell in deprived urban areas as the prevalence in this study was 5.2% which is equal to the 2011 census data and the 2011 General Household Survey [8] which reported that the highest prevalence occurs amongst the Black Africans, who generally reside in under-resourced communities. Not all of those identified as having a disability were interviewed but the questionnaire was filled in by 85% of PLWDs, which is a reasonable response rate.

There is a large unmet need for rehabilitation services and assistive devices, in that approximately one third of the respondents reported that they needed services but that they had not accessed them. This was in contrast to general health services which been consulted by all but 2.5%, a surprisingly high number as it has been noted that people with chronic illnesses and

disability often do not access health systems adequately [10]. The reason for this discrepancy may be that there are a large number of community health clinics in the area under study, as the Health Care 2010 strategy of the Western Cape, has focussed primarily on curative and preventative strategies [11]. However, few of them have rehabilitation personnel and those with disabilities might have found it difficult to attend clinics if they were not in the near vicinity, as borne out by the large number citing financial and transport difficulties. There is a system of designated transport for those with disabilities in the Cape Metro (Dial-a-Ride), but again, the participants did not seem to access the existing service.

A worrying finding was that over half of the participants over 65 years of age had not had access to services. The elderly represent a particularly vulnerable group and this group should be targeted in any attempt to expand services. However, it does not appear as if the cause of disability is associated with access, as 40–50% of those whose disability was caused by unintentional injury, maternal/child health factors or chronic diseases of lifestyle. Those with infectious diseases had had more access to services.

The number of people requiring rehabilitation for physical functional limitations was the highest, however the number of people requiring rehabilitation for limitations related to sensory and language functioning represented a larger proportion of those reporting unmet needs. It would appear that a range of services

529 need to be made more available, ranging from physiotherapy to
530 speech and language therapy and audiology. The inadequate
531 provision of assistive devices, including wheelchairs and walking
532 aids reflects the disadvantage of the participants as these devices
533 are readily available to those who do manage to access the public
534 sector. This failure to access services was similarly identified by
535 Sharma who reported that older African Americans “continue to
536 remain in poorer health despite access to care and insurance
537 status... (and that) underutilization accounts for some of this
538 observed disparity” [12].

539 The limitations of the study include the need to rely on self-
540 report which may have over- or under-estimated the need and/or
541 access. A comparison of self-report, clinical examination and a
542 standardised measure of work-related limitation for monitoring
543 activity limitations, demonstrated a considerable differences in
544 results. Self-reported limitations were higher than from those
545 derived from clinical examination or the use of a standard
546 measure of functional capacity [13].

547 However, the information relating to service need and
548 utilisation may be equated with an assessment of the performance
549 of the respondents and their interaction with environmental
550 factors. This is defined in the ICF as “involvement in a life
551 situation or the lived experience of people within the actual
552 context in which they live” (P229) [1]. It is difficult to obtain
553 objective data regarding these experiences and the researcher is
554 usually reliant on self-report data, with all their limitations.

555 The results of this study indicate an urgent need to improve
556 access to rehabilitation services, including the provision of
557 assistive devices to people with disability living in this impover-
558 ished area. Physiotherapy and home based care in particular
559 were identified as being required by several people. There seemed
560 to be less awareness of the contributions of other rehabilitation
561 professional and there may be a need to raise awareness of the role
562 of speech and language therapists, audiologists, occupational
563 therapists and psychologists. There is currently a programme
564 underway to train home based carers to meet the needs of the
565 community as identified through the larger study. However, it
566 would be important that the training incorporate management of
567 not only physical but sensory and language functional limitations
568 as well. Prescription, supply and fitting of assistive devices may
569 well be beyond the scope of the home based carers skills and as
570 35.5% reported the need for such devices, it may be important that
571 the home-based carers be supported by a network of therapists
572 who are able to guide, train and supervise their training and
573 management of patients and who are able to provide specialist
574 support where necessary.

575 The local authorities seem to have made reasonable headway
576 with the provision of health care services; however the provision
577 of rehabilitation services that would appear to impact positively
578 on the QoL of people with disabilities is lagging behind. The
579 Report suggests that, where services are minimal, basic rehabili-
580 tation services should be developed within the existing health
581 infra-structure [2]. In the light of the relative accessibility of
582 health care services, this might be a very useful strategy. The

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595 training of home based carers as community-based rehabilitation
596 workers is another strategy that could be employed, as discussed
597 above. However, it should be remembered that South Africa is
598 categorised as a middle and not a low-income country and the
599 sophisticated service coverage available to those with higher
600 incomes should ultimately be expanded and the service quality
601 improved. The most disadvantaged people in the one of the most
602 disadvantaged communities in Cape Town surely have the right to
603 access appropriate care.
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605 Declaration of interest

606
607 The authors report no conflicts of interest. The authors alone are
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611

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