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The Perceived Needs-Access Gap for Health Services among Persons with Disabilities in a Rural Area Within South Africa

Disability and Health

Research Paper

Richard Vergunst,

[Alan J Flisher Centre for Public Mental Health, Department of Psychology, Stellenbosch University, Stellenbosch, South Africa]

Leslie Swartz,

[Alan J Flisher Centre for Public Mental Health, Department of Psychology, Stellenbosch University, Stellenbosch, South Africa]

Karl- Gerhard Hem,

[SINTEF Technology and Society, Department of Health, PB 124 Blindern, 0314 Oslo, Norway]

Arne Henning Eide,

[SINTEF Technology and Society, Department of Health, PB 124 Blindern, 0314 Oslo, Norway]

[Centre for Rehabilitation Studies, Stellenbosch University, Stellenbosch, South Africa]

Hasheem Mannan,

[School of Nursing, Midwifery & Health Systems, Health Sciences Centre, University College Dublin, Dublin, Ireland]

Malcolm MacLachlan,

[Assisting Living & Learning (ALL) Institute, Maynooth University, Ireland; Centre for Rehabilitation Studies, Stellenbosch University, South Africa; Olomouc University Social Health Institute, Palacky University Olomouc, Czech)]

Gubela Mji,

[Centre for Rehabilitation Studies, Stellenbosch University, Stellenbosch, South Africa]

Marguerite Schneider,

[Alan J Flisher Centre for Public Mental Health Department of Psychiatry & Mental Health,
University of Cape Town]

Corresponding author

[Dr Richard Vergunst, Alan J Flisher Centre for Public Mental Health, Department of
Psychology, Stellenbosch University, PO Box X1, Matieland 7602, Stellenbosch, South
Africa rvergunst@sun.ac.za]

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Abstract

Purpose: Health should be a universal phenomenon. However, little is known about the relationship between disability status and health issues – particularly in rural areas. This study looks at health issues of persons with disabilities in Madwaleni, a rural impoverished area in South Africa in 2011, and compares them to persons with no disabilities.

Materials and Methods: Standardised questionnaires were used in the survey to assess disability and health status. The sample comprised of 773 individuals – 322 persons with disability and 451 comparisons (without disability) – covering 527 households. Children under the age of five were excluded from the sample. We used purposive sampling.

Results and Conclusion: This study found that persons with disabilities have poorer reported health outcomes than persons with no disabilities. There is also an association between disability severity and mental health issues as assessed by the GHQ-12. A significantly higher percentage of persons with disability did not get health care when needed. Persons with disabilities also have less favourable attitudes towards competence of health care workers. This study has shown greater health needs and less satisfaction with services, which strongly indicates insufficient access for persons with disabilities in a rural impoverished area within South Africa.

Keywords: Rural Health, Disability, South Africa

- Persons with disabilities in rural South Africa have poorer reported health outcomes.
- Persons with disabilities have less favourable attitudes towards competence of health care workers in rural South Africa.
- Better access to health care for persons with disabilities is needed in rural South Africa.

Introduction

Although health should be a universal opportunity, this is not the case for many subsections of society [1], including persons with disabilities. Despite general agreement that health is not experienced equitably [2], there is relatively little research looking specifically at potential disparities between disability status and health [3]. This is especially relevant for impoverished communities where there is an association between poverty and increased need for health care [4]. Poverty in a community makes the right to health care a “distant dream” [5,p.1173]. This study looks at the relationship between disability and health in an impoverished rural context within South Africa.

Disability and inequity in health

The United Nation’s [6] Convention on the Rights of Persons with Disabilities (UNCRPD), Article 25, states the necessity of care for persons with disabilities – it is not just a moral or universal obligation but a human right. The enjoyment of the highest attainable standard of health without discrimination on the basis of disability is highlighted in the Convention.

Within South Africa, Section 27 of the Bill of Rights of the Constitution of South Africa 1996 affirms that everyone has the right to access to health care services and places an obligation on the state to take reasonable legislative and other measures within its available resources to achieve the progressive realisation of this right.

Disability is an emerging field within public health [7]. International academic communities, clinical experts, and activists for persons with disabilities agree on the importance of health care services, and they argue that appropriate health care should be guaranteed for the entire population [8,9]. Persons with disabilities have specific and general health care needs.

However, health care needs that are not met and that exacerbate health disparities are experienced disproportionately by persons with disabilities [10,11]. The World Report on

Disability [3] as well as others [12] claim that doctors who lack training about disability frequently compromise patients' health care experiences and health outcomes. Emerson [13] identifies five key factors in the health inequalities of persons with disabilities which include poor access to health care, social determinants of poor health, intrinsic health vulnerabilities, communication difficulties and level of health literacy and lifestyle risk factors.

There is a growing body of evidence that persons with disabilities experience lower health status (both physically and psychologically) as well as excess burden of disease [3,14,15], but still a broader recognition of these health disparities is needed [16]. As Krahn et al. [7] state, future research and policy directions should address health inequities for persons with disabilities. There is still little known about health care experiences among persons with and without disabilities [17] and this lack of knowledge about the actual dynamics, and experiences in obtaining health care is alluded to by Sharby et al. [18] when they state that persons with disabilities often require more and different interventions and accommodations to receive adequate health care.

The health of persons with disabilities in developing countries has not received enough attention in the literature [19]. Trani et al. [19,p.1483] found in their study in Sierra Leone that persons with disabilities "were more likely to report poorer health status" than persons with no disabilities. Mulumba et al. [20] found that participants in Uganda viewed their disability as a barrier to good health. This is despite some persons with disabilities having increased health needs [21,22]. Moodley and Ross [1] found in South Africa that persons with disabilities reported poorer health as well as higher incidence of communicable and non-communicable diseases.

Disability and access to health services

Lack of access to health care can affect an individual's health status, exacerbate existing health problems, and increase the risks for individuals developing new health problems that could have been prevented [23]. The relationship between disability and health care has received relatively little attention, despite it being important in terms of providing equal opportunities [15]. Persons with disabilities are among the most vulnerable groups of any population and are often excluded from mainstream health services [24]. WHO [3] state that persons with disability commonly need to be able to access appropriate mainstream health care and rehabilitation to a greater extent than persons without disability, because in addition to having the same health needs as others, they may have higher levels of need related to their impairments, health conditions, or the lifestyle consequences of these. It is, however, fully recognised that disability need not, and sometimes should not, be construed as a health problem [25].

While there is evidence in South Africa that suggests that policies are good, implementation may be failing persons with disabilities on these issues [26,27]. Maart et al. [27] go on to say that disability in South Africa is framed within a medical and welfare framework which results in the exclusion of persons with disabilities and their exposure to health access barriers. This is because of the strong emphasis on medical needs and a neglect on wider social needs resulting in the exclusion of persons with disabilities from mainstream society. The authors argue that government strategies should be focussed on universal access for persons with disabilities, and placing disability within a human rights framework.

Despite the fact of further access needs, and a gap between needs and services offered, persons with disabilities constitute a marginalised group in health services research. Their experiences within the health care system are not well understood, and research-based health service improvement interventions rarely take the interests and particular needs of individuals

with disability into account [28]. Only recently has a disability perspective been included in some health service research projects [29,30].

Disability and rurality

According to the WHO [3], there is a higher prevalence of disability in rural areas compared to urban areas. Roughly four of every five persons with disabilities live in rural areas in developing countries [31,32]. There is scarce data on their health needs [33]. What little literature there is suggests that persons with disabilities in rural areas experience barriers to health care [23,34,35] as well as low health status [36,37].

There is little understanding of how poverty and disability interact in the rural context, where access to services and employment is often more limited [26]. According to Grut et al. [24,p.1], poor people with disabilities who live in poor rural societies “experience unique problems”. The right to health care in rural areas is compromised by a number of health system and socio-economic barriers [38]. The “triple vulnerability” – poverty, disability and rurality – has undergone limited research in terms of health status.

Disability and health in rural communities in South Africa

Only a few studies in rural South Africa [24,27,39–41] have specifically addressed disability and access to health care. Neille and Penn [39], in a qualitative study, found that barriers to service provision extend beyond physical obstacles and include a variety of sociocultural and sociopolitical barriers. Braathen et al. [40] describe the struggle to access health care for someone with a psychosocial impairment in a rural area. Grut et al. [24], also using a case study of a person with a disability in rural South Africa, show how people with disabilities who live in poverty-stricken areas experience multiple barriers. Maart et al. [27], however, found that persons with disabilities in the rural areas of the Eastern Cape perceived fewer

barriers within their environment (with the exception of attitudes) than those residing in informal urban settlements in the Western Cape. The study by Jelsma et al. [41], on the other hand, looked at people with disabilities in rural Eastern Cape and concluded that a rural setting seemed to contribute to a worse perceived health-related quality of life.

While there has been research on access to health care, there has been a paucity of research assessing health status for persons with disabilities. This needs to be prioritised – especially in South African rural areas. Mechanisms leading to disparities in health status and the appropriateness of health services in impoverished rural populations needs to be understood in order to guide development towards equity in health.

This study aims to address this shortcoming and will look specifically at perceptions of health and associated health services among rural persons with disabilities and a systematically sampled comparison group.

Methodology

Context of study

This paper was part of a larger international project – the EquitAble Project (see www.sintef.no/Projectweb/Equitable). This international project was a four-year collaborative (2009-2012) research project comprised of researchers from Ireland, Norway, Sudan, Namibia, Malawi and South Africa looking at access to health care for vulnerable people in resource poor settings in Africa.

This paper is based on the findings in Madwaleni, one of the four settings used in South Africa. Data was collected in October-November 2011. The context of this study is the catchment area of Madwaleni Hospital, South Africa. The hospital is situated in a deeply rural

and impoverished area of the Eastern Cape Province, 220 km up the coast from East London, 100 km from Mthatha, 30 km from Elliotdale and 16 km from the Wild Coast. The Madwaleni area is situated in the rolling hills of the Amatole District within the Mbashe Municipality. This rural area is defined by poor infrastructure, lack of basic service provision, low levels of literacy, high levels of unemployment, limited access to health care and education, high incidence of communicable diseases and high mortality rates [39].

Sample of study

The sample comprised of 773 individuals – 322 persons with disability and 451 controls (without disability) – covering 527 households. Children under the age of five were excluded from the sample. We used purposive sampling to first select four health centres surrounding the hospital, then random sampling to select the villages surrounding the health centres, and finally systematic sampling to select the households within the villages. Household questionnaires were administered with the head of the household to ascertain if the household had a person with a disability or not. Disability was defined by using the Washington Group Questions (WGQ) on Disability, wherein if an individual has “some difficulty” with two or more of the six questions, or has “a lot of difficulty” or is “unable to do” for one or more questions, they may be categorised as a person with activity or functional limitations, and categorised as “disabled”. Further details of the sampling and categorisation of participants have been reported by Eide et al. [42].

The Household questionnaire is a questionnaire administered to the head of the household in each household (after consent forms were completed). The Household questionnaire ascertained the composition of the household, i.e., the members of the household, and whether or not they had a disability using the Washington Group (WG) Questions on disability. If a person with a disability was identified in the household, then that person completed consent

forms and was also interviewed using the questionnaire for persons with disabilities. This questionnaire focused particularly on health and access to health care. If there were more than one person with a disability in a particular household, the person with the most severe disability was interviewed. This was ascertained by the disability rating scale in the household questionnaire where a higher total disability score according to the Washington Group method depicted more severe disability. This questionnaire focused particularly on health and access to health care. A third interview (after completion of consent forms) was carried out in the same household with a person without disability (in-house controls) matched to the person with disability by age (five year latitude either way) and gender using a Control questionnaire. This questionnaire is a shortened version of the one administered to individuals with disability. If no matched non-disabled control was found in the household, no control interview was carried out in that household. If the household did not have a person with disability living in the house then this household became a neighbourhood control household. The head of the household would complete the Household questionnaire and a randomly selected person (using random tables) in the control household would complete the control questionnaire (neighbourhood controls). The sample used in the study was not a representative sample of the population. Characteristics of the Head of Household in this sample is that 66% of households were headed by women with an average age of 56 years. The average age for men-headed households was 55 years. Of the 532 households, there were 112 only case households, 175 only control households and 245 case and control households.

Instruments

The questionnaires used in the survey were developed by a research team as part of a large international research project (Equitable) in four African countries. This study reports on parts of the questionnaires from the larger project that related to disability, health, and attitudes.

Interviews using three questionnaires were conducted in the study:

1. A household questionnaire.
2. A questionnaire for a person with a disability.
3. A control questionnaire for a person without disability.

This study used the Washington Group questions on disability [43] and the GHQ-12 questions [44] on mental health from the questionnaires from the larger study, as well as more general questions on physical health, mental health, “not getting health care” and “attitudes towards health care”. The WG questions comprise 6 items measuring difficulty with six core functional domains (using a 4 point Likert scale including “No”, “Some”, “A lot” and “Unable” options). The GHQ-12 is a self-administered screening instrument with 12 items to ascertain mental health status of an individual with a yes/no response format.

In terms of ascertaining physical and mental health, there were two single questions asking about their respective health, using a scale from 1 (poor) to 4 (very good).

When ascertaining access to health care, there were two questions from the questionnaire – one asking a direct question about getting health care when needed, with a yes/no option, followed by a list of possible reasons why they did not get health care when they needed it.

Ascertaining attitudes towards health care was done through 9 items each with a four point Likert scale ranging from “strongly disagree” to “strongly agree”.

The survey questionnaires, which were originally in English, were translated into isiXhosa and back-translated to make them more appropriate for the study site and its community members. The 17 data collectors/interviewers (all community health workers from the area)

made use of cell-phone technology for data capturing and the data were then sent to a central data base where they were collated and analysed. This method provides more accurate data than the traditional paper version, reduces missing data considerably, is easier to monitor locally and remotely, and has built-in quality checks [45].

Statistical analysis

The approach to data analysis for this paper included quantitative data analysis using descriptive and inferential statistics. We performed frequency and cross tabulation, comparing and contrasting the frequency of different phenomena between persons with disabilities and persons with no disabilities using Chi-squared tests, Analysis of Variance (ANOVA) and Regression Analysis.

Ethical approval for the overall study was obtained from the ethics committee of Stellenbosch University while ethics approval for doing research in Madwaleni was obtained from the Department of Health, Eastern Cape Province, South Africa.

Results

The sample comprised 58.2% persons without disabilities (in house and neighbourhood controls) and 41.8% with disabilities (cases). The majority in the sample were in the 18-60 year age bracket, well over half were females, most respondents were currently married and most reported less than primary education. More individuals with disabilities were in the 61+ years age range and fewer were between 18-60 years ($\chi^2 = 96.92$, $df = 1$, $p < .001$). Females were in the majority among both disabled and non-disabled (n.s.). More disabled than non-disabled had no formal education ($\chi^2 = 89.39$, $df = 1$, $p < .001$).

[Table 1 near here]

General physical and mental health

Asked about their general physical and mental health on a scale of 1 (poor) to 4 (very good), persons with disability score lower than non-disabled on both (physical health: $\chi^2 = 102.36$, $df = 3$, $p < .001$, mental health: $\chi^2 = 75.44$, $df = 3$, $p < .001$). Still, more than half of individuals with disabilities (57.7 %) state that their physical health is either good or very good. While as many as 70.4 % of persons with disabilities rate their mental health to be either good or very good, the corresponding figure for non-disabled is as high as 92.0 %.

[Table 2 near here]

Further to assessing subjects' mental health, questions from the General Health Questionnaire (GHQ-12) were also part of the individual survey. The GHQ-12 is a measure of psychological morbidity [44]. Analysis of the twelve individual items on the GHQ-12 showed eight of the items to be significantly different between the two groups and to the disadvantage of persons with disabilities. Also the four non-significant differences were to the disadvantage of persons with disabilities (see Table 3). The largest difference in percentage points between disabled and non-disabled were for *Feeling useful* (34.8) and *Not able to face problems* (32.3).

[Table 3 near here]

For all single items in Table 3 (except with one item – “Lost much sleep”) more persons with disabilities scored negative as compared to persons with no disabilities.

Scalability analysis resulted in $\alpha = 0.86$ for the twelve items which were subsequently added together to form a scale with range from 0-12. A maximum score of 12 indicated the highest level of reported psychological problems and a minimum score of 0 indicating no psychological problems. Mean scale value was 4.21 for persons with disabilities and 2.71 for non-disabled ($F = 425.44$, $df = 1$, $p < .001$) and thus supports the general mental health rating discussed above.

Adding the WG scale items produced a “disability scale” with range from 6 to 18, mean value 7.67, and standard deviation 2.27.

Bi-variate regressions of WG6 (disability), age, sex and level of education on mental health (GHQ 12) were carried out. Associations were significant for all except for level of education. This variable was, however, also included in the multivariate model due to level of significance being $< .02$. The multivariate regression showed that mental health problems (GHQ 12) increased with severity of disability and were higher among females as compared to males. Age turned negative in the multivariate analyses due to its association with age, and no association was found between level of education and GHQ 12 (see Table 4).

[Table 4 near here]

Not getting health care

A significantly higher percentage of persons with disabilities did not get health care the last time they needed it (direct question, yes = 1, no = 2) (24.4%), compared to persons with no disabilities (12.6%) ($\chi^2 = 17.77$, $df = 1$, $p < .001$).

When considering reasons for not getting health care, cost and having no one to accompany oneself to go to health care were the only statistically significant factors that distinguished persons with no disabilities and persons with disabilities who did not get health care. Of persons with disabilities, 74.0% stated cost as a factor in not getting health care, while only 3.8% of non-disabled did the same ($\chi^2 = 66.33$, $df = 1$, $p < .001$). On the other hand, 13.5 % of non-disabled stated that they had no-one to accompany them, while the corresponding figure for persons with disabilities was 4.2 % ($\chi^2 = 4.24$, $df = 1$, $p < .05$).

Attitudes towards health care

The attitudes of health care users towards competence of health care personnel differ significantly between the two groups. Persons with disabilities have less favourable attitudes towards competence of health care workers, have less trust in the treatment and are more negative to the way they have been received by health personnel. For these three indicators, results are very similar for health clinic and the hospital. When this is said, it suffices to say that the overwhelming majority of both disabled and non-disabled provide positive responses to the competence, trust in treatment as well as the way they have been received. The difference between persons with and without disabilities lies in many respondents with disabilities tending to answer “agree” rather than “strongly agree” to the questions (see Table 5).

[Table 5 near here]

Bi-variate regressions revealed no significant association between getting health care the last time needed and any of the attitude to health care variables in Table 5. However, GHQ 12 was positively associated with not getting health care (OR = 1.17, 95 % CI = 1.13 – 1.20). This means that the likelihood of getting health care the last time needed was reduced with higher levels of GHQ/mental problems.

Discussion

This study in a rural area within South Africa confirms earlier studies [1,14] that persons with disabilities have poorer reported health outcomes than persons with no disabilities. Mental health problems increase with severity of disability and females had more mental health problems than males. Fewer individuals with disabilities get health care when they need it and have less positive attitudes to health personnel than non-disabled.

The results from this study confirm studies from other parts of the world. However, not many studies have looked at the issues of disability and health care in rural areas. In South Africa, 52% of the total population and 75% of poor South Africans live in rural areas [46]. It is therefore important that disability research in South Africa includes looking into the context of rurality. The study has pointed to some factors that are key in explaining the current situation of health inequity, such as higher health needs and negative attitudes towards health personnel. Although the study does not enable analyses of causes of negative attitudes, we can assume that this at least partly is due to negative experiences. Shakespeare and Kleine (47) have for instance highlighted attitudinal barriers that prevent persons with disabilities from having their health needs met.

In terms of health issues for persons with disabilities in Madwaleni, we need to find recommendations and solutions. As Casey [48,p.179] states, accessing health care is a multi-level process. Interventions beyond health care access are required to meet health care needs of rural residents with disabilities [49]. A person with disability living in Madwaleni is not only about the “medical” issues but more importantly about social and inclusion issues. As Swartz and Watermeyer [50] state, the story of disability in South Africa, as well as in other countries, is about social oppression. There is still much to do before persons with disabilities

in general, and those living in rural impoverished areas in particular, can be included in all parts of society including health care.

This study has clearly indicated insufficient access. According to Tomlinson et al. [9,p.1857], there is insufficient information available about effective interventions that work to improve the lives of people with disabilities, and the results call for “urgent attention to the issue of access to appropriate health care for people with disabilities especially in low income and middle income countries”.

As Yee and Breslin [51] state, the removal of barriers would only be “a critical first step” toward achieving the broad public policy change needed for sustainable and equitable health care for persons with disabilities. According to these authors, such changes will only occur if the health care system recognises that equitable health care – health care that addresses the different needs of different types of people – is a priority.

There are limitations with this study. Firstly, the study used self-reported measures to assess health. These measures may be biased. The participants, if they perceived the responses to be socially desirable, may have incorrectly reported the information [52]. The face-to-face interviews may have influenced the outcomes and, as Saulo et al. [53] point out, personal interaction affects the conversation. There were no independent confirmations by anybody of what the participants were reporting. This study only included reports from survey respondents and no formal assessments from health care staff or other informants. It was thus a subjective rating. Despite these limitations, which are common to many similar studies, particularly in the hard-to-reach rural areas we report from – this research also had several strengths. The relatively large sample size, the systematic approach to sampling and the use of a contextually relevant comparison group, allows our research to make a unique contribution

to the literature. This paper is also supported by the parallel qualitative data that was part of the larger international Equitable project. This qualitative data adds depth to the statistical analysis of this paper [23,54]. These qualitative findings show that persons with disabilities face unique problems in accessing health care ranging from transport issues to attitudinal issues.

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Declaration of interest

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Table 1. Sample of individuals with and without disabilities

Variables	Non-disabled		Disabled		Total	
	N	%	N	%	N	%
Age (N = 773):						
5 – 17 years	30	7.7	19	5.0	49	6.3
18 – 60 years	330	84.2	217	57.1	547	70.9
61+ years	32	8.2	144	37.9	176	22.8
Sex (N = 720):						
Male	109	29.9	100	28.2	209	29.0
Female	256	70.1	255	71.8	511	71.0
Level of education (18+) (N = 720):						
No formal education	91	24.9	206	58.0	297	41.3
Less than primary school	181	49.6	113	31.8	294	40.8
Primary school	80	21.9	27	7.6	107	14.9
Secondary school	12	3.3	6	1.7	18	2.5
Tertiary level education	1	0.3	3	0.8	4	0.6

Table 2: General physical health and mental health rating

	General Physical Health (N = 771)				General Mental Health (N = 772)			
	No Disability		Disability		No Disability		Disability	
	N	%	N	%	N	%	N	%
Poor	10	2.6	66	17.4	8	1.8	13	4.0
Not very good	55	14.1	95	25.0	28	6.2	50	15.5
Good	154	39.4	156	41.1	229	50.9	207	64.1
Very good	172	44.0	63	16.6	185	41.1	53	16.4

Table 3: Comparisons between persons with and persons without disability in their psychological morbidity (GHQ-12) (N = 765 - 772)

	No Disability		Disability		Chi square		
	N	%	N	%	X ²	df	p
Been able to concentrate	329	83.9	206	54.2	80.10	1	< .001
Lost much sleep	117	29.8	108	28.5	0.17	1	n.s.
Feeling useful	308	78.6	203	53.8	52.70	1	< .001
Been capable of making decisions	323	82.6	228	60.5	46.38	1	< .001
Felt constantly under strain	101	25.8	121	32.2	3.76	1	n.s.
Cannot overcome difficulties	108	27.6	131	34.7	4.54	1	< .05
Been able to enjoy day to day activities	314	80.1	234	61.9	31.06	1	< .001
Been able to face problems	322	82.1	225	59.8	45.58	1	< .001
Been feeling unhappy	100	25.5	118	31.1	3.01	1	< .001
Been losing confidence	88	22.6	91	24.2	0.29	1	n.s.
Been thinking you are worthless	79	20.2	84	22.5	0.58	1	n.s.
Been feeling reasonably happy	285	72.7	234	61.9	10.22	1	< .01

Table 4: Regression analysis of disability, age, sex and level of education on mental health (GHQ 12: anxiety and depression) (N_M = 702)

Variables	Bivariate regression			Multivariate regression		
	Beta	t	p	Beta	t	p
WG6 (disability)	0.23	6.41	< .001	0.22	5.44	< .001
Age	0.08	2.27	< .05	-0.01	-0.12	n.s.
Sex	0.08	2.15	< .05	0.08	2.12	< .05
Level of education	-0.05	-1.42	0.16	-0.01	-0.13	n.s.

Table 5: Attitudes towards health care

		Non-disabled	Disabled	X ²	df	p
Health personnel at local clinic have appropriate competence (N = 771)	Strongly disagree	3.3	6.9	73.55	3	< .001
	Slightly disagree	4.1	8.2			
	Slightly agree	8.4	28.5			
	Strongly agree	84.2	56.5			
Health personnel at hospital have appropriate competence (N = 763)	Strongly disagree	2.3	4.8	69.72	3	< .001
	Slightly disagree	2.8	4.3			
	Slightly agree	6.4	27.2			
	Strongly agree	88.5	63.7			
Trust the treatment provided by personnel at local clinic (N = 772)	Strongly disagree	0.3	2.6	81.48	3	< .001
	Slightly disagree	1.8	4.7			
	Slightly agree	9.9	32.9			
	Slightly disagree	88.0	59.7			
Trust the treatment provided by personnel at the hospital (N = 769)	Strongly disagree	1.0	2.7	73.56	3	< .001
	Slightly disagree	2.6	4.5			
	Slightly agree	6.1	27.6			
	Strongly agree	90.3	65.3			
People are received in a positive manner at local clinic (N = 772)	Strongly disagree	1.3	3.4	74.52	3	< .001
	Slightly disagree	3.1	3.2			
	Slightly agree	7.7	30.8			
	Strongly agree	88.0	62.6			
People are received in a positive manner at the hospital (N = 762)	Strongly disagree	2.0	3.0	54.40	3	< .001
	Slightly disagree	1.8	3.0			
	Slightly agree	6.1	24.5			
	Strongly agree	90.0	69.5			