

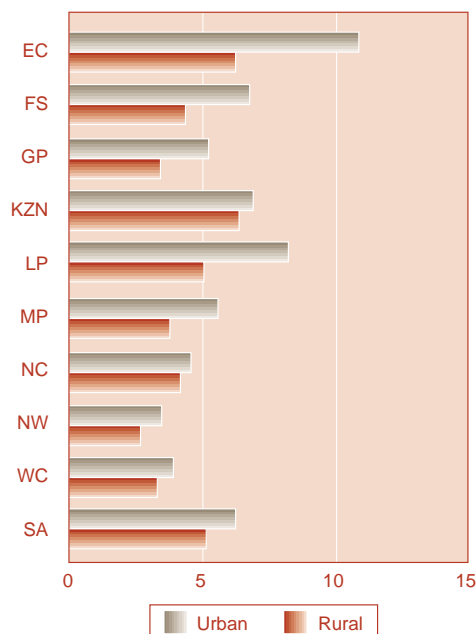
# DISABILITY AND DISABLEMENT



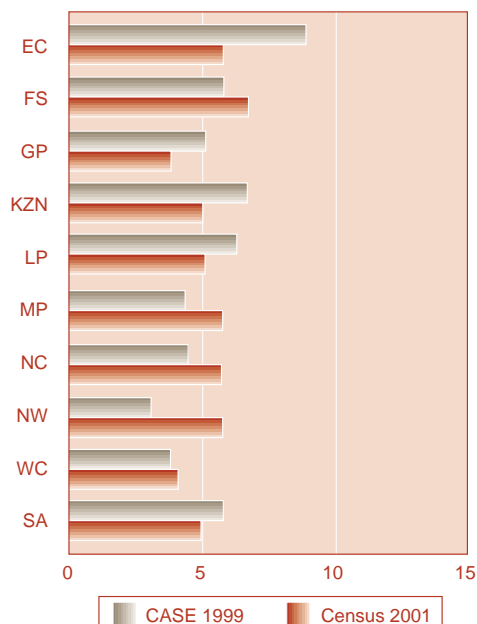
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## Prevalence of disability, urban and rural (CASE 1999)



## Prevalence of disability, CASE 1999 and Census 2001



## Key Messages

- ◇ Available quantitative data on disability prevalence rates need to be interpreted with caution.
- ◇ The construct, concept and definition of disability/ disablement is complex and needs to be recognised by all stakeholders.
- ◇ Quantitative data on its own is insufficient to describe the experience of being disabled.
- ◇ The development of disability indicators should be informed by previous work at district level.
- ◇ Serious attention needs to be paid to the monitoring and evaluation of disability prevention and rehabilitation (including CBR) programmes.
- ◇ People with disabilities are not a homogeneous group and inequities exist especially among those people with unseen disabilities (e.g. people with cognitive and psychiatric impairments).

## Framework for Monitoring and Evaluation

Global:

- ◇ Global Burden of Disease Project
- ◇ WHO International Classification of Functioning, Disability and Health (ICF) 2001

South Africa:

- ◇ Health Goals, Objectives and Indicators 2001-2005 (limited)

## Key Indicators

Prevalence of disability (overall, age-specific and by particular types of disability)

## Key References and Data Sources

- ◇ National Disability Survey (CASE 1999)
- ◇ Census 1996, 2001
- ◇ Burden of Disease estimates for SA, 2000

## Introduction

Recognising that any attempt to describe disability from a purely quantitative perspective fails to adequately describe the disability experience or quantify the impact of disability, the emphasis of this chapter is on quantitative data in as much as it highlights shortcomings in available information, and provides an important basis for the development of disability indicators. This is done against a backdrop of changing health profiles and needs in South Africa (SA) as well as new approaches to quantifying disease burdens in which the prevalence and severity of disability is a key consideration.<sup>1</sup>

Attempts have been made to describe the epidemiology of disablement in SA, using data from the national population censuses<sup>2,3</sup> (1996 and 2001), the first National Disability Survey of 1999,<sup>4</sup> and data from smaller district population-based household disability prevalence surveys. Although these data have some limitations, a picture of the size and nature of the disablement burden is beginning to emerge.

There are very few data on how this burden is distributed between different geographical regions and population and age subgroups, which makes it difficult to demonstrate inequities. However, prevalence rates for some of the diseases responsible for disablement suggest that inequities do exist. Lack of hard data describing the epidemiology of disability is a recurring theme and has important implications for the recommendations of this chapter.

## Framework for Monitoring and Evaluation

### Burden of disease and disability

Improved survival in HIV-uninfected individuals has resulted in increasing burdens of diseases with non-fatal outcomes and a burgeoning population with functional disabilities, and against this demographic and epidemiological background, there has been a growing imperative to quantify burdens of morbidity and disability.<sup>1</sup> The importance of disability in constructing Burden of Disease (BoD) estimates has been emphasised through the Global Burden of Disease Studies (GBD) carried out by the World Health Organization.<sup>5</sup>

BoD information is an important component of health information for monitoring the health of the nation. Detailed BoD information linked with cost-effectiveness analyses inform priority setting for health sector reform. The monitoring of equity in service delivery to people with disabilities is an important consideration.<sup>6</sup> There are also some difficulties in estimating the full effect of *years lived with a disability* (YLDs) since disabilities vary enormously in duration and severity from one disease state to another and more than one disease can combine to influence the extent of disability in any individual. Furthermore, the degree of disability will depend on the availability and effectiveness of treatment for that disabling condition and the extent to which adaptations in the environment limit the impact of the disability.<sup>7</sup>

In BoD calculations different values are assigned to time lived at different ages. This 'age weighting' is intended to reflect different productivity at different stages of the life cycle and, thereby, assigns a different social value to lives lived at different ages. The effect of this is to reduce the *disability-adjusted life years* (DALYs)<sup>a</sup> lost by premature death in children with developmental disabilities and to potentially lower the relative importance of these conditions in decisions about resource allocations.<sup>8</sup> However, disability weighting does not take into account the way that individual and social resources can compensate for the level of disability experienced. The failure to factor in these compensatory mechanisms distorts BoD estimates and undervalues the therapeutic and rehabilitation benefits offered by rehabilitation professionals and programmes.

### Definitions and classifications of disability

A lack of consistency and consensus regarding the definition of disability is a major stumbling block in identifying people with disabilities, the development of disability indicators, disability research, and the development and implementation of disability policies.

Traditionally, disability was defined as a "restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being".<sup>9</sup> This definition is located within a medical model which views disability as a problem of the person, directly caused by disease, trauma or another health condition, and which requires medical care provided in the form of individual treatment by professionals. Disability activists<sup>b</sup> who regard disability as a human rights and a development issue and who espouse a social model in which disability is viewed as "a complex system of social restrictions imposed on people

a DALYs are a single measure of BoD, using time to equate death and disability, it comprises 'years of life lost' (YLLs) due to premature mortality and 'years lived with a disability' (YLDs), weighted according to the severity of disability.

b Disabled People International (DPI) was formed in 1981 at the Rehabilitation International Congress in Winnipeg, Canada.

with impairments”, have challenged this definition.<sup>10</sup> Disability is thus defined by Disabled People International (DPI) as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level due to physical and social barriers”. Disability as a category can only be understood within a framework, which suggests that it is culturally produced and socially structured.<sup>11</sup>

Worldwide consultation by WHO with disability groups and professionals attempted to address some of these critiques and the International Classification of Impairment, Disability and Handicap (ICIDH) framework was completely revised in 2001. The International Classification of Functioning, Disability and Health (ICF)<sup>12</sup> provides a bio-psychosocial framework for considering the prevalence and risk factors for disabilities, based on a disease-oriented or ‘medical’ model, while also offering a more holistic approach to the classification of functioning within social and environmental contexts, based on the ‘social’ model.

In 1980, Wood coined the term disablement<sup>13</sup> to describe the planes of experience relating to impairment, disability and handicap. Disability refers to the condition while “disablement is a collective descriptor referring to any experience identified variously by the terms impairment, disability and handicap to describe the state of the person with a disability.” ‘Disablement’ may be a helpful umbrella term to use when referring to prevalence of disability.

Until consensus is reached on key definitions, obtaining accurate disability data and the development of indicators to measure disability and rehabilitation programmes will remain problematic.

## The development of global, national, provincial and district disability indicators

The development of global disability indicators is in its infancy.<sup>14</sup> The South African national Department of Health (NDoH) Health Goals, Objectives and Indicators (HGOI) 2001-2005<sup>15</sup> contain the core indicators that are of interest to the national department. Provincial and district rehabilitation and disability indicators should be linked to the District Health Information System (DHIS). To date, limited human resources and capacity at a district level has resulted in the lack of development of disability indicators at a district or provincial level.<sup>c</sup>

### Suggestions for development of disability indicators

Three basic requirements are necessary for the development of disability indicators:<sup>16</sup>

- ◆ **Terminology** i.e. consensus on definitions of impairment and disability;
- ◆ **Methodology** i.e. the identification and recording of people with disabilities. This requires dedicated human resources at the district level to initiate and sustain the collection of routine data for an information system; and
- ◆ **Information (data)** i.e. valid estimates of disability prevalence by age group and gender.

Disability indicators could include:

- ◆ general indicators: e.g. who are, and what is the size of, the target group;

**Table 1: National Health Goals, Objectives and Indicators**

Goal	Objective	Indicator
Prevent and control non-communicable chronic diseases (i.e. hypertension, diabetes, asthma)	Improve quality of care to people with chronic diseases	Proportion of emergency admissions (<75 years) of persons with hypertension
Improve the quality of life of people with disabilities	Increase accessibility of health services to people with disabilities	Percentage of people with disabilities who have accessed basic rehabilitation services
Eliminate avoidable blindness due to cataracts by 2020	Increase cataract surgery rate to 1 per 1000 population by 2005	Cataract surgery rate per year

Source: HGOI 2001-2005<sup>15</sup>

Note: The first and third goals are related to disability prevention; only the second goal relates to people with disabilities generally.

c Tshivhase M, Department of National Health: Subdirectorates Chronic Diseases, Geriatrics and Disabilities, October 2003, personal communication.

- ◆ childhood disability indicators e.g. what percentage of children experience different disabilities by age and gender;
- ◆ rehabilitation service indicators e.g. input, output, effects<sup>d</sup> and impact indicators.

The lack of routine baseline data also affects the monitoring of disability prevention programmes. Disability prevention is an essential component of primary health care (PHC). A framework for primary, secondary and tertiary prevention has been described under strategies below; however no data are presently being collected to monitor existing programmes.<sup>17</sup>

Currently there are only two projects in SA which have attempted to collect information for district disability indicators:

The Health Information Systems Pilot Project (HISPP)<sup>18</sup> (1995-1998) proposed that data collection should be based on goals, targets and indicators. It was suggested that data on disability should be collected at local level monthly and annually.

An outcome of this project was the development of the South African Christian Leadership Assembly (SACLA) Disability Information System in Cape Town (2000). This aimed at improving the recording, analysis, and summarising of client and rehabilitation staff data, in order to facilitate the availability of information for use in the planning and management of the rehabilitation project.<sup>19</sup>

The Disability Information Project,<sup>17</sup> working in two sub-districts in KwaZulu-Natal, attempted to develop a set of disability indicators for the DHIS. The project demonstrated that much of the information collected by government and non-government sectors was not being used, and that even when data were compiled and reported to the provincial Department of Health (KwaZulu-Natal Rehabilitation Programme) they were not used effectively to influence action. The disability related information required at district level is :

- ◆ Information regarding disability resources (i.e. a resource directory); and
- ◆ Information to measure interventions or services being rendered (i.e. baseline information and indicators).<sup>17</sup>

## Strategies

### Disability prevention and rehabilitation in PHC

#### *Primary disability prevention<sup>e</sup>*

Primary prevention of disabilities in low- or middle-income countries is often concerned with many of the same causes that are responsible for high mortality rates. Although there are no specific data to support this view, it is speculated that in SA, where prenatal conditions, congenital abnormalities, injuries and cerebro-vascular insults make increasingly larger contributions to burdens of disease, effective primary prevention activities for these conditions, where feasible, may significantly reduce disabilities across the lifespan.<sup>20</sup>

#### *Secondary disability prevention<sup>f</sup>*

It is anticipated that as the health transition deepens in SA, a greater emphasis will be placed on secondary prevention, much of which should take place in health facilities at different levels in the health system. Examples of early intervention programmes are the prevention of hearing impairment due to identification of otitis media and the early diagnosis, management and harm reduction for chronic diseases such as hypertension, diabetes and asthma.<sup>21</sup>

#### *Tertiary disability prevention<sup>g</sup>*

The major emphasis in addressing disability in most developing countries has been on tertiary prevention. Initiatives for tertiary prevention in SA have come from rehabilitation professionals and community development workers who have promoted the concept of community-based rehabilitation (CBR) programmes. CBR programmes provide support and services to people with permanent disabilities, using approaches and models of delivery considered appropriate for settings with severe personnel and physical resource constraints. They aim to combine direct and indirect therapeutic inputs by health and rehabilitation workers with support and training for families and caregivers in addition to societal interventions to limit stigma and equalise opportunities in all walks of life.

The district is the main level of implementation in these programmes and the level at which health, social development and educational inputs are integrated in rehabilitation programmes that address disabilities from birth through infancy and early childhood into formal educational and work environments.<sup>22</sup>

d Effects are the changes in knowledge, skills, attitudes and behaviour of the target group that result from disability and rehabilitation services: e.g. what percentage of parents of disabled children know about resources such as schools, NGOs and support groups providing services for disabled children?

e Primary disability prevention consists of measures to prevent diseases, injuries, or conditions that can result in impairments or disabilities. Such measures include health education, immunisation, maternal and child health services, and safety promotion.<sup>21</sup>

f Secondary prevention consists of early intervention in the treatment of diseases, injuries, or conditions to prevent the development of impairments.<sup>21</sup>

g Tertiary prevention includes all measures to limit or reduce impairments or disabilities. It also includes the treatment of disabilities, or rehabilitation.<sup>21</sup>

### Community-based rehabilitation (CBR) services in SA

CBR<sup>23</sup> has been advocated and practised in different provinces of SA since the early 1980s and has been accepted by the NDoH in its Rehabilitation Strategy,<sup>24</sup> but no specific funding or resources have been made available for CBR programmes. Although to date, approximately 267 Community Rehabilitation Facilitators (CRFs) have been trained in SA, it has now been proposed by the Rehabilitation Professional Boards that in future the mid-level training will not be generic but discipline specific e.g. for Occupational Therapy, Physiotherapy and Speech and Hearing Therapy.

Perhaps the lack of awareness of the value of CBR programmes is linked to the lack of research and evaluation of CBR programmes. However, many questions remain about CBR and the field is criticised for having poor indicators with which to measure success.<sup>25</sup>

### Gaps in disability prevalence data

Numerous methodological problems are encountered in the collection and interpretation of prevalence data on disability and these include:

- ◆ The definition of disability used and whether it is disability or impairments which are being measured or described (most disability data actually refers to impairments, rather than disability);
- ◆ Whether the disability was merely reported versus confirmed;
- ◆ Criteria used to determine the severity of disability (i.e. whether it was mild, moderate or severe);
- ◆ The categories used to classify the different types of disability;
- ◆ Multiple disabilities / impairments where a disabled person may have more than one impairment – do the researchers count the people or the impairments?
- ◆ The use of proxy versus direct reporting, which may contribute to the underestimation of milder and non-visible types of disabilities / impairments.

These considerations need to be borne in mind when using, analysing or interpreting disability prevalence data.

## Data

### Disability databases (Routinely collected data)

In SA there have been recent improvements in epidemiological databases for some specific conditions, which make an important contribution to disability burdens, such as HIV/AIDS, notification of congenital defects (i.e. the birth defects register) and certain cancers. However, measures of types, severity or duration of disability are not usually included in these databases.

### National Population Census Data

It is only in the past two population censuses (1996 and 2001) that data on disability have been collected. Data from these censuses provide information about serious and largely visible disability and gives some indication of the prevalence of multiple disabilities. However, the questions used to capture serious disability were changed between the two censuses, making direct comparisons between the two data sets difficult. In addition, as the questions were answered by household respondents and mainly identified individuals with severe disabilities, there is some concern that the prevalence of disabilities was underestimated.<sup>h</sup>

### Population-Based National Disability Survey

Disability surveys usually involve two phases: a screening phase for reported disability and a follow-up phase which confirms the disability status of those screened positive, as well as a 10% sample of those screened negative for reported disability. The screening questions are related to disability (e.g. "Does anyone in this household have difficulty walking or moving around?"), and the follow-up phase is related to impairment ("What is the reason for this difficulty?").<sup>26</sup> The household screening questionnaire used in disability surveys that have been conducted across the lifespan in SA have been based on the WHO Disability Questionnaire<sup>27</sup> which identifies people who report disability or health problems affecting their functional ability. In these surveys a follow-up interview generally used the criteria from the International Classification of Impairments, Disabilities and Handicaps (ICIDH)<sup>12</sup> to confirm impairment in the second phase. A substantial shortcoming of these studies has been the lack of adequate questions to screen for learning / cognitive / mental and psychiatric disabilities.

The only SA national disability survey was commissioned by the NDoH and conducted by the Community Agency for Social Enquiry (CASE) in 1999.<sup>4</sup> This population-based survey was not a two-phase survey as described above. It only described

<sup>h</sup> Statistics South Africa, 2003, personal communication.

reported disability. However it did attempt to capture the “lived experience” of people with disabilities through in-depth interviews.

Data from this survey provide some indication of the broad categories of rehabilitation inputs required to address the needs of people with moderate and severe disabilities (Table 2). These data do have limitations, but should be evaluated within the context of the main objective of the survey; to address the needs of policy-makers, service providers and the disability sector itself. It provided a representative population-based estimate of reported moderate to severe functional disability across all ages, all provinces and all major population groups. It was particularly concerned with capturing the social dimensions of disablement

and in understanding limitations of functioning in relation to the social and environmental contexts within which people live.

Despite the fact that the population census data and the national disability survey (CASE 1999) cannot be directly compared due to the different questions and methodology used, it is interesting that similar crude prevalence rates for serious reported disability were obtained in both the national census and the national disability survey (Table 2).

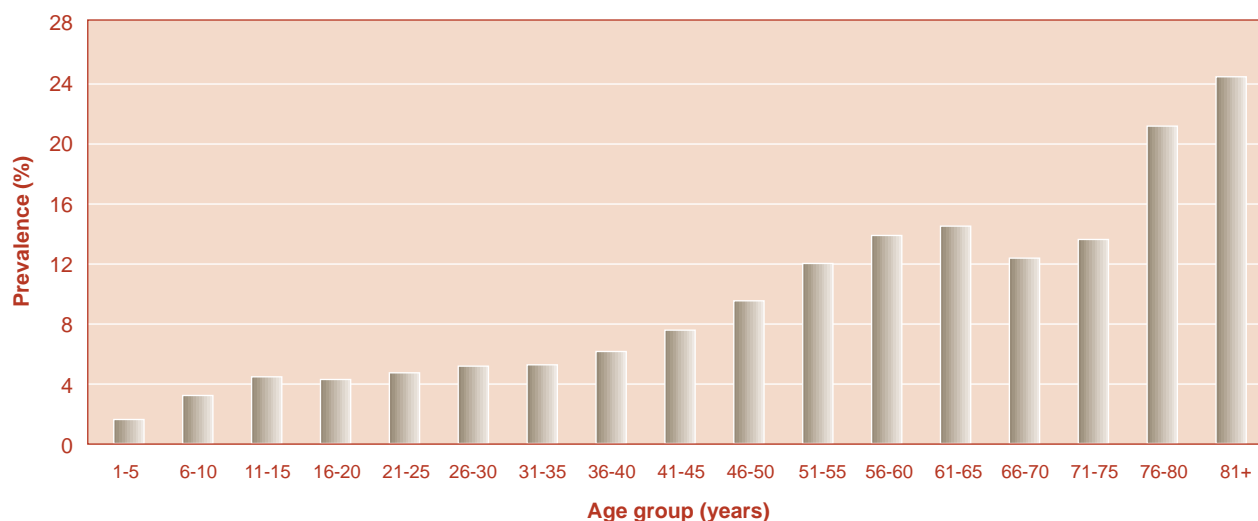
More than half (58%) of the individuals included in the CASE national disability survey had more than one reported disability and almost a third had more than three reported disabilities.

**Table 2: Prevalence of reported disability, by type of disability (%), 1996, 1999 and 2001**

Disability Types (Census)	Census 1996	Census 2001	Disability Types (CASE)	CASE 1999
Sight	2.7	1.3	Seeing	1.7
Physical	1.4	1.2	Movement	2.0
Hearing	1.0	0.7	Hearing	1.0
Mental / Emotional	0.5	0.6	Emotional	1.1
Multiple	-	0.6	Multiple	-
Intellectual	-	0.5	Intellectual	1.1
Communication	-	0.2	Communication	0.8
Learning	-	-	Learning	1.2
Crude prevalence rate	6.5	5.0	Crude prevalence rate	5.9

Sources: National disability survey (CASE 1999), Census 1996 and 2001

**Figure 1: Prevalence of reported disability by age (%)**



Source: National disability survey (CASE 1999)

**Table 3: Prevalence of reported disability by province and area (%), 1999 and 2001**

Province	CASE 1999			Census 2001
	Urban	Rural	Overall	
Eastern Cape	10.9	6.2	8.9	5.8
Free State	6.7	4.3	5.8	6.8
Gauteng	5.2	3.4	5.2	3.8
KwaZulu-Natal	6.9	6.4	6.7	5.0
Limpopo	8.2	5.1	6.3	5.1
Mpumalanga	5.6	3.8	4.5	5.8
Northern Cape	4.6	4.1	4.5	5.7
North West	3.4	2.7	3.1	5.8
Western Cape	3.9	3.3	3.8	4.1
South Africa	6.3	5.1	5.9	5.0

Source: National disability survey (CASE 1999) and Census 2001

**Table 4: Prevalence of reported disability by population group and gender (%), 1999**

Population group	Male	Female	Overall
African	6.5	5.8	6.1
Coloured	5.1	3.9	4.5
Indian / Asian	5.5	3.9	4.7
White	6.3	5.1	5.7
Total	6.4	5.5	5.9

Source: National disability survey (CASE 1999)

**Table 5: Reported causes of disability (%), 1999**

Causes of reported disability	%
Illness	26
Unknown	21
Birth and related causes	19
Accident / injuries	15
Other	9
Violence and crime	5
Witchcraft	3
Ageing process	2
Total	100

Source: National disability survey (CASE 1999)

**Table 6: Household disability prevalence surveys (1986-2002) across the lifespan**

Published	1986	1987	1991	1992	1993	1993	1995	1995	2000	2002	
<b>Province</b>	WC (Urban)	KZN (Rural)	LP (Rural)	NW (Rural)	LP (Rural)	GP (Urban)	WC (Urban)	KZN (Rural)	LP (Rural)	KZN (Rural)	
<b>Author</b>	Disler <sup>28</sup>	McLaren <sup>29</sup>	Anderson <sup>31</sup>	Cornielje <sup>30</sup>	Concha <sup>32</sup>	Cornielje <sup>33</sup>	Katzenellenbogen <sup>34</sup>	Irlam <sup>35</sup>	Christianson <sup>36</sup>	Couper <sup>37</sup>	
<b>Age range</b>	All Ages	All Ages	All Ages	All Ages	All Ages	All Ages	All Ages	2-19 years	2-9 years	0-10 years	
<b>Methods</b>	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist No severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> Clinical examination No follow-up by therapist Severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist No severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist Severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist No severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist Severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist Severity grading	2-phase survey WHO Q – 1 <sup>st</sup> ICIDH – 2 <sup>nd</sup> No clinical examination Follow-up by therapist Severity grading	2-phase survey TQP – 1 <sup>st</sup> ?method – 2 <sup>nd</sup> Clinical examination No follow-up by therapist No severity grading	2-phase survey TQP – 1 <sup>st</sup> ?method – 2 <sup>nd</sup> Clinical examination No follow-up by therapist No severity grading	2-phase survey TQP – 1 <sup>st</sup> ?method – 2 <sup>nd</sup> No clinical examination Follow-up by therapist No severity grading

## Data from disability prevalence surveys across the lifespan

The disability prevalence surveys across the lifespan that are described here were small-scale population-based surveys confined to a geographical region or health district. Seven district household disability surveys (across the lifespan)<sup>28-34</sup> were conducted in SA from 1986-2002, mainly in low resource settings in rural areas. Although similar methods were used, the surveys are not comparable due to a number of methodological problems, which result in variable prevalence rates (Table 6).

## Data from childhood disability prevalence surveys

Three rural childhood disability prevalence surveys<sup>35-37</sup> were conducted between 1992 and 2002. When judged against the exacting methodological standards recommended for two-phase surveys, they do not satisfactorily meet all the criteria and thus the methods used may have resulted in prevalence rates that deviate significantly from the true rate in these populations. The prevalence rates for all categories of developmental disability in these studies vary from 1.6 to 6.0%.

## Data from disability specific surveys

The only two domains of functioning where specific impairment prevalence rates are available are vision and hearing. SA data for visual impairment,<sup>i</sup> blindness and partial sight come from population-based studies conducted in Limpopo<sup>38</sup> and KwaZulu-Natal<sup>39</sup> (Table 7). There are no accurate population-based data on childhood blindness for SA.<sup>40</sup>

**Table 7: Prevalence of visual impairment (%)**

	Limpopo 1988	KwaZulu-Natal 1993
Visual impairment <sup>i</sup> (6/60)	-	1.4
Blindness (3/60)	5.7	1.0

Sources: *Bucher and Ijsselmuiden*,<sup>38</sup> *Cook, Knight and Crofton-Briggs*<sup>39</sup>

Most studies on hearing loss in SA have focused on children of school-going age and have been school-based or hospital-based rather than population-based.<sup>42-45</sup> The only prevalence study done on first year entry (Grade 1) school children, in the industrial areas of Witbank / KwaGuqa,<sup>46</sup> gave an overall crude prevalence rate for mild hearing impairment of 6% and for bilateral sensorineural deafness of 0.2%.

No population-based studies have been done on hearing impairment in adults. Hearing loss is an accompanying feature of ageing and it is to be expected that there will be a significant increase in hearing loss and deafness with age. The estimates of overall crude prevalence rates for hearing impairment across the life span as given by the Deaf Federation of SA (DEAFSA) are shown in Table 8.

**Table 8: Estimates of crude prevalence for hearing impairment (%), 2004**

Range of hearing impairment	Prevalence rate (%)
Mild	6
Moderate	3
Severe / profound	1
Total rate hearing impairment	10

Source: DEAFSA

## Analysis

The analysis and interpretation of the available quantitative data on disability prevalence in SA is limited by the inconsistencies in definitions used, what was being measured and by the methodological constraints and differences outlined earlier. Another problem is the involvement of many disciplines in the disability field, each with its own conceptual framework, tradition and service.

The overall reported serious disability rates varied between 6.5% (1996) and 5% (2001) in the Census data whilst the rate in the CASE study was 5.9%. In all these surveys, physical (or motor) and visual impairments were the most common and not surprisingly, prevalence rates increase with age. There is some evidence to suggest that this rate varies considerably between different population groups and that there is a difference between rural and urban areas, with more people with disabilities living in urban areas.

The CASE data (Tables 3 and 4) shows significant population group and gender variations such as:

- ◆ Africans had the highest prevalence rate (6.1%);
- ◆ Males are more likely to be reported as being disabled than females in all groups, although the only significant finding was for Africans; and
- ◆ African males are the most likely to be reported as being disabled.

<sup>i</sup> Assessment of vision ranges from normal vision (6/6), to vision which can be corrected with spectacles (6/18), to visual impairment that includes partial sightedness and low vision (6/60), to blindness (3/60).



## Conclusions and Recommendations

Although the disability prevalence rate for Africans is higher than for other population groups these variations are less striking than they are for mortality and disease-specific morbidity profiles in these same population groups.<sup>j</sup> In the absence of confirmed impairment data, this finding is difficult to interpret.

The data also suggest that differences between the provinces exist with overall prevalence rates being higher in the poorer regions i.e. Eastern Cape and KwaZulu-Natal (Table 3). Consequently, generalisation of the overall disability prevalence rate to these sub-groups should be avoided. There are substantive differences between provincial disability rates when comparing the census data to the national disability survey, therefore recommendations on allocation of resources on an equitable basis cannot be made with confidence.

There is less consistency in the prevalence rates for the different functional domains apart from the observation that physical (motor) and visual impairments appear to be the most common disability types reported (see Table 2 and 6). The rates for both intellectual and emotional or learning problems varied from 0.5 to 1.1% across the studies, highlighting the fact that within categories or types of disability, cognitive and psychiatric impairments, which are largely “invisible” disabilities are the most difficult to identify and are thus particularly poorly described in all disability surveys. Within disability research, there has been a tendency to focus mainly on the more “visible” disabilities, such as motor, vision and hearing. A substantial concern is the lack of appropriate questions to screen for mental / cognitive and psychiatric disabilities as well as epilepsy.

There are very few reliable data for cause-specific disability.<sup>17</sup> Given the way that disability was defined in the CASE study, it is possible that a substantial proportion of disability is due to *chronic diseases* rather than neurological or neuromuscular conditions or injuries that impact on activities of daily living. As the breakdown by cause was based on historical data and often obtained by proxy reporting rather than from affected individuals, only coarse categorisation of cause was possible (see Table 5). Nevertheless the fact that over 50% of causes are ascribed to illness or are unknown, reinforces the suggestion that many of these disabilities are a consequence of chronic diseases. This may also help to explain why prevalence rates increase with age. The major reported causes of disability were illness (high blood pressure, epilepsy, ear infection, psychiatric illness, hereditary illness, diabetes, arthritis, polio), birth-related incidents and accidents. This finding has implications for disability prevention programmes.

- ◆ Despite the limited population-based disablement information available to assist in planning for rehabilitation and disability support services, both the national population census (2001) and the national disability survey (1999) have arrived at overall reported rates for moderate to severe disability of approximately 6%, suggesting that this figure provides some basis for quantifying the disability burden in SA.
- ◆ However, the limitations of the available data regarding prevalence rates impact on planning and resource allocation and on the development of disability and rehabilitation indicators. It is not possible to develop disability and rehabilitation indicators in the absence of basic data e.g. the denominator. The lack of pre-determined disability and rehabilitation indicators affects feedback on the effectiveness of services and compromises the monitoring of policies and programmes.
- ◆ The lack of consensus regarding definitions and classification of disability stemming from the different models (medical, social and human rights) makes data collection a formidable task. There needs to be a concerted attempt to use the International Classification of Functioning, Disability and Health in SA.
- ◆ The absence of provincial and district disability indicators impedes progress towards setting up and monitoring rehabilitation services and disability support programmes.
- ◆ The size, nature and distribution of the disablement / disability burden in SA needs to be described through well-designed, standardised, two-phase district prevalence studies. These data are required to guide health policy, the appropriate training of rehabilitation professionals, decisions about the need for mid-level rehabilitation workers and the provision of rehabilitation services. Thereafter, they are needed to monitor the effectiveness of these inputs and interventions.
- ◆ Standardised second-phase follow-up examination surveys are recommended in order to obtain reliable age / gender and cause / impairment specific prevalence data for morbidity events and disabilities.

It is recommended that:

- ◆ The development of disability indicators needs to be carried out urgently. At district level, data describing disability prevalence, types and causes of disability (impairment), are

<sup>j</sup> Solarsh G, 2004, personal communication.

required to guide primary, secondary and tertiary disability prevention efforts and for the assignment of priorities in disability prevention strategies.

- ◆ Indicators to measure the impact of CBR programmes are urgently required so as gauge the need for training community rehabilitation facilitators or other discipline-specific mid-level rehabilitation workers.
- ◆ The inequities experienced by people with cognitive and "invisible" disabilities need to be documented in relation to the collection of disability prevalence survey data. This is also important with regard to the type of disability / impairment as well as access to all disability and rehabilitation services: viz. health, education, employment, social services, transport, housing and sanitation.
- ◆ Ethical considerations need to be taken into account when establishing databases as personal details contained in the records could infringe on an individual's right to privacy.

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