



# Chapter 10

## Disability



### 10.1 Introduction

The 1997 White Paper on an Integrated National Disability Strategy (INDS) noted that there is a lack of reliable information on disability in South Africa. However, although available data cannot provide a perfect portrait of disability in South Africa, it can provide a rough sense of the scope of disability<sup>25</sup>. Internationally, it has been suggested that as much as 10 per cent of the world's population live with disability. Estimates suggest that moderately to extensively disabled people constitute around 5 per cent of developing country populations.

A special disability survey of South Africa conducted in 1998 by the Department of Health and the Community Agency for Social Enquiry (Case) estimates that approximately 5,9 per cent of South Africa's population is comprised of disabled people. This compares with an estimate of 5,2 per cent from the 1995 October Household Survey (OHS), 12,8 per cent of the National Health & Population Development: South African national survey of 1996 and 6,6 per cent from the 1996 census, and 3,7 per cent from the 1999 OHS. The variance of these measurements illustrates the difficulty of making a reliable estimate of disability; since the underlying population characteristics are unlikely to have changed dramatically since 1995, differences in prevalence estimates mostly reflect differences in the survey instruments and techniques.

The broad scope and the many socio-economic repercussions of disability make it, by any measure, an important policy issue for South Africa. The impact of disability extends well beyond the disabled themselves. Disability

touches the lives of friends, family, and fellow community members. Indeed, while individuals bear the brunt of illness and impairment, disability also creates hardships for those who care for and depend on disabled family members. At least 16 per cent of South Africans are themselves disabled or live in a household with a person who is disabled, according to the 1999 OHS – and this is possibly a conservative estimate.<sup>26</sup> A first step in formulating a national policy framework to address disability is to acknowledge the scope of the problem.

### 10.2 The demographics of disability

Disability tends to follow certain patterns with respect to age, income, and employment. Older people are more likely to have a disability. This is due in part to increased probability of serious health problems and in part to accumulated risk of suffering a disabling accident over the course of their lifetimes. While the elderly account for the largest share of the disabled population, children account for a disproportionately small portion of national disabilities. Disability among children is, however, a major concern. The impact of disability on the lifetime outcomes of children can be extraordinarily high. Children with disabilities tend to have lower school attendance rates, less education, and ultimately, additional barriers to independent living and engagement with society. According to the 1999 OHS, nearly 30 per cent of school-age children with disabilities were not attending school or not attending full time, compared with 10 per cent of children without disabilities.

Poor individuals make up a disproportionately large share of the disabled population. Disability tends to be more common among poor people for two reasons:

- First, poverty increases vulnerability to disability, chiefly through poor nutrition, difficulty accessing adequate basic healthcare, lack of knowledge about prevention, and the greater concentration of poor workers in dangerous jobs.
- Second, disability increases vulnerability to poverty: lower education, discrimination in the labour market (both active and institutional), special disability-related costs, and in some cases the need for other household members to spend time and resources supporting disabled family members increases the likelihood that disabled people will remain – or become – poor.

The 1999 OHS suggests that while less than 2 per cent of individuals living in households with monthly incomes above R10 000 are categorised as disabled, the disability rate was more than twice as high for individuals living in households with monthly incomes below R1 200.

Men are slightly more likely to live with disability after accounting for age effects, probably due to the dangerous jobs many men hold. Although men may be marginally more likely to experience disability, the qualitative experiences of women with disabilities may be much more difficult. The 1997 White Paper on INDS acknowledges that disabled women must endure the oppression of a patriarchal society, which can be magnified for those women who cannot perform even the traditional roles of motherhood and homemaking. Women who bear disabled children may even in some cases be subject to the scorn and rejection of the community.

### 10.2.1 The imperative to act

Not only is the impact of disability widespread but it is likely to increase for the foreseeable future. This trend has been noted at the international level, where violence and ageing populations are driving forces. In sub-Saharan Africa the situation is considerably worse, due in large part to the projected impact of HIV/AIDS on the health and well-being of the region. Therefore, not only must we recognise the scope of disability as it affects society, but so too must we recognise the urgent need to put in

place measures to address the growing threat of disabling disease.

These imperatives to action are not new. Indeed, South Africa has for some time recognised the need to provide special protection to people living with disabilities. The foundation for this protection is established in section 9 of the Constitution, which prohibits discrimination on the basis of disability. These notions have found affirmation in the decisions of the Constitutional Court and in a series of international agreements to which South Africa is committed<sup>27</sup>.

The 1997 White Paper on an INDS provides the basis for national disability policy:

- Disability affects a significant share of the country and places a significant drain on the human resources of people with impairments as well as their families.
- The incidence of disability in South Africa is set to rise, in line with international trends.
- South Africa has a clear legal commitment to address disability. This commitment is enshrined in the Constitution, affirmed by the Constitutional Court and reaffirmed by international agreements to which South Africa is a signatory.

## 10.3 Findings

### 10.3.1 Conceptualisation and definition of disability and implications for national policy

The present disability definitions that underpin current social security provisioning are for various reasons problematic. They are (a) based entirely on the medical model; (b) are constructed in such a way as to undermine the policy objective of maximising full participation in the world of work by creating a disincentive to work; and (c) do not take into account social and labour market barriers, as well as broader social and environmental factors which inhibit labour market participation.

### 10.3.2 Consequences of disability

Disability bears certain economic consequences and is closely related to poverty because it makes

households more vulnerable to poverty and poverty-creating shocks and disabled people themselves face additional barriers to education, employment, and access to basic services (like transport) that conspire to keep them poor. The opposite is also true, namely that poverty increases the risk of disability.

It also has social consequences in the awareness and attitudes of the public. Sometimes overtly, sometimes unintentionally, society discriminates against people with disabilities. Legal measures, and even fundamental constitutional rights, cannot alone redress the prejudices of the public.

### 10.3.3 Progress and gaps in the current framework

Progress in the present system is mixed. According to the INDS the present social security legislative framework, its administration and allocation systems tend to be discriminatory, punitive, insensitive to the specific needs of people with disabilities, uncoordinated, inadequate and riddled with high levels of fraud. In defence of the state it must be said that the State has, however, managed to create and maintain a system of reasonable coverage for a relatively large group of adults with disabilities. The provisioning for children with disabilities is far less successful.

Of most immediate concern to Government is the need to improve access to official support, basic services, and also effective means of adjudication when disabled people are deprived of these rights. Among the most consistent complaints in the social security system are those concerned with the poor administration of public support for disability.

## 10.4 Integrating disability measures into social security

### 10.4.1 Fundamental principles and legislative framework

It must be recognised that people with disabilities are not a homogenous group, but have a wide range of needs and circumstances that contribute to their well-being and opportunities in life. Even persons with similar disability types have

completely different social, financial and physical environments that directly impinge on their capacity to function at their maximum potential. This must be recognised when designing a sensitive and holistic social security system that attempts to meet the needs of this group.

**10.4.1.1** Currently the different pieces of legislation regarding the various schemes of social security are fragmented, sometimes contradictory, and make for gaps in provisioning. Hence the attempt to arrive at a comprehensive system might necessitate one overriding piece of legislation, such as a Social Security Act, which would incorporate the concept of social security for disabled people, its aims and objectives, as well as highlighting the purposes and eligibility criteria of each scheme, including the social assistance programmes.

**10.4.1.2** There may still be need for separate legislation and regulations to guide each of these schemes, but these must be consistent with the fundamental principles embodied in the Act. There needs to be some “linking” and cohesiveness between the different social insurances and the legislation. For example, at present the Employment Equity Act calls for the employment of persons with disabilities, while reintegration into the labour market is not a goal of COIDA. This mix of policy and legislation should ensure that the guidelines set out in the various policies are achieved and enforced through the necessary legislation and regulations.

**10.4.1.3** Particular attention should be paid to clear definitions in the Act(s) that can be operationalised in the regulations, with accompanying guidelines for their implementation.

**10.4.1.4** With regard to legislation for children, both the Child Care Act and the Social Assistance Act should provide for social security for children with disabilities. A combined approach, with the Child Care Act determining the rights and the package of benefits, while the Social Assistance Act incorporates the finer practical details and regulations, might be useful and ensure a comprehensive approach, but may be cumbersome for implementation.

### 10.4.2 Concept of social security for disabled people

**10.4.2.1** Social security systems should be seen not merely as safety nets and poverty alleviating measures, but also as measures to

promote self-sufficiency and independence.

**10.4.2.2** Social security should protect societal members from and compensate for, the financial consequences of a number of social contingencies or risks, including those preventative and rehabilitative measures. It should ultimately aim at societal solidarity, and at the full development, equality and participation of persons with disabilities (UN Committee on Economic and Social Rights - General Comment No. 3. Para 11)

### 10.4.3 Definition of disability

**10.4.3.1** In light of the differing definitions and measurements of disability used in the various pieces of legislation regarding social security, it is suggested that a broad concept of disability be used. This could be adapted for more specific definitions in each scheme, dependent upon the purpose and coverage of each. Obviously the definitions must be 'operationalised' in the assessment tools, which must accurately translate the concepts within the purpose into simple and measurable criteria.

**10.4.3.2** It must also be stressed that the system should not define beneficiaries according to the disability, but should rather determine provisioning in response to need.

### 10.4.4 Purposes and eligibility criteria

Within the broad concept of social security mentioned above, there could be specific purposes of each of the social security measures. For example, the purpose of COIDA could be to provide for the compensation of an injured person or his/her dependants for work-related incidents resulting in injury, death, or an occupation disease, in order to enable their full rehabilitation, retraining and re-integration into the labour market.

**10.4.4.1** Persons with disabilities, physical, sensory, mental and intellectual, who cannot provide for their basic needs, should be eligible for the disability grant. In addition, it is suggested that persons with chronic illnesses, including HIV/AIDS, should also qualify for the grant.

**10.4.4.2** Eligibility should not be based on the person's "incapacity" to work, as often their lack of work is due to the poor economic climate and prejudice in the work place, as opposed to their physical or mental inability to perform the job.

**10.4.4.3** Eligibility should be determined by a Needs-based Assessment. This should replace the current means testing.

### 10.4.5 Assessment procedures

**10.4.5.1** The assessment procedure should encompass a "needs-assessment" which considers not only the type and severity of disability or illness, but other social, economic, physical and environmental factors. Persons with the same disability can have very different needs, depending on all these factors and on the support structures and resources available to them.

**10.4.5.2** The assessment should also focus on the applicant's capabilities, rather than only on the degree of disability, as well as their potential for re-training and re-employment. Relevant training and reintegration measures should also form part of the package of social security.

**10.4.5.3** The International Classification of Impairment, Disability and Handicaps (ICIDH-2), which is currently being developed by the World Health Organisation, may be useful in indicating the main categories and indices for measurement.

**10.4.5.4** The assessment form must include all the disability categories, i.e. physical, mental, sensory and intellectual (currently it only includes physical and mental).

**10.4.5.5** An appeal mechanism (such as a Review Tribunal) is necessary for those rejected applications, and must consist of relevant intersectoral representatives.

### 10.4.6 Targeting

**10.4.6.1** The issue of means testing versus universal provisioning is complex and represents the contradiction, or struggle, between the fundamental rights to social security and the available resources.

**10.4.6.2** Obviously resources are not infinite and personal or company income tax systems are exhaustible as sources of financing for social security systems. Thus efficient allocation of resources to suit the presenting needs of the population is required. In the face of limited resources, some form of targeting measure, to identify the most in need, is essential. However, this must be viewed within the rights-based framework as stipulated by the South

African Constitution and the various international instruments, which stress the basic rights of persons with disabilities to social security and social assistance, with progressive realisation and within the constraints of available resources.

**10.4.6.3** It is suggested that a thorough system of ‘needs-assessment’ as described above, would include analysis of a person’s financial situation and their need. Some threshold level of income, in relation to need, would have to be determined. It is suggested that the Disability Sector and economists undertake this.

**10.4.6.4** It is important that the tools of targeting be sensitive and accurate in determining “need” versus purely a medical diagnosis emphasising categories of disability.

**10.4.6.5** This assessment should be undertaken at regular intervals, so as to re-assess the level of need and to adjust the benefits accordingly. Sudden termination of grants is strongly discouraged. There should be adequate warning of the gradual ‘phasing’ out of payments.

### 10.4.7 Benefits

**10.4.7.1** A system making use of a needs-based assessment as described above, would then provide a sliding scale of benefits, to suit the range of presenting needs within available resources. This should incorporate cash transfers and other indirect forms of social security.

**10.4.7.2** The provision of cash transfers is an essential means to alleviate poverty, to smooth the income cycle, to meet those special needs due to the disability, and to overcome barriers that many persons with disabilities face in maximising their development and potential. For these reasons the disability grant and the CDG must be maintained and kept at their current level, if not increased.

**10.4.7.3** The Committee recommends persons with disabilities and in poverty receive basic income as a first step in the package of benefits. Thereafter, consideration should be given to their special needs and provision be made in the form of “topping up” in relation to cash benefits, in-kind benefits and other essential services.

**10.4.7.4** It is recommended that the Grant-in-Aid be re-examined and its usefulness and relevance determined. In addition, a brief analysis of the Department of Social Development’s provisioning of “personal assistants” should be undertaken. Some scope of choice in personnel by the beneficiary would be advised.

**10.4.7.5** Changes in thinking over recent years have led to a lower emphasis on institutional care for those with disabilities. It is widely recognised that effective de-institutionalisation requires adequate support at a community level. In the case of residential care, a major barrier to discharge is that many patients have no effective family links and, if discharged, would be without shelter. This process must therefore be properly resourced.

A submission to the Committee from the Department of Health expressed concern for those with mental disabilities particularly. In their instance, co-ordination is essential between the Department of Health, Labour (which runs protective and sheltered workshops) and Prisons (as many as 30% of prisoners may suffer from mental illnesses).

## 10.5 Short-term measures

- Suggested immediate amendments to the Social Assistance Act and regulations and to the Department of Social Development’s administrative structures.
- Remove the clause of “permanent home care” for eligibility of the CDG.
- Extend the CDG to children with moderate disabilities and those in special schools or day centres.
- Revamp the current medical and assessment forms. Include sensory and intellectual disabilities. The disability sector could assist with this process.
- Utilise a multi-disciplinary panel for assessments.
- A disability representative should be present on all the boards examining claims for insurances.
- Develop clear eligibility criteria and guidelines for assessors.
- Remove the criteria of spouse’s income in the means test. Only the income of the person with the disability should be measured, not the “household” income.
- Provide free health services to persons with disabilities.
- Establish a review process for cases at regular intervals.
- Establish an appeal mechanism.

- Increase the back-pay to 6 months.
- Speed up the time of processing claims for grants and insurances.
- Educate the public on the social security available to them.

## 10.6 Recommendations

In general, policy should stay focused on improving the preconditions for equal participation, even as more general efforts at bolstering the capacity for governance and administration in the system of social protection move forward. The emphasis should be on promoting independent living, not institutional care. Specific and *achievable* policy recommendations are needed to promote action and not just further deliberation.

- Retain existing social assistance disability benefits until such time as income support measures are universally implemented, with the real value of the current disability grant being taken into account as well as other government measures.
- In-kind benefits should be de-linked from cash benefits. If people with disabilities take jobs and become disqualified from receiving public income support, they should not be required to give up access to non-cash support. De-linking cash and non-cash benefits may help to reduce the strength of the welfare trap around the means test.
- The present disability definitions are for various reasons unacceptable, as they are constructed in such a way (a) as to serve as a disincentive to work; and (b) that they overemphasise capacity for labour market participation, and do not take into account social and labour market barriers, as well as broader social and environmental factors. It is, therefore, proposed as a short-term measure that the said definitions be amended so as to reflect an interactive approach, which takes into account both medical condition and social and environmental factors.
- It is further proposed that the definitions be widened in order to include four main categories of disability, namely physical, mental, sensory and intellectual disability.
- It is also suggested that the ICIDH-2

approach to the definition of disability could be helpful, as it stresses three main elements, namely: (i) anatomical malfunctioning; (ii) the impairment of normal human functions as a result of the condition; and (iii) the question whether the condition hamper or impair the ability to socially integrate.

- An amended definition should serve two main purposes, namely, firstly, to identify whether the person concerned is indeed covered according to the revamped (wider) definition and, secondly, to identify the appropriate range and level of transfers (cash or in-kind benefits, goods and/or services) required to address the needs of the particular person according to the particular kind of disability suffered by the individual.
- Provision should be made for the purchasing of *essential* assistive devices. Procedures for acquiring simple assistive devices should be simple and costs should be subsidised.
- Simplify administrative procedures. Although administration needs greater resources and capacity building, it should also be an aim of government to reduce bureaucratic complexities that further complicate applications for social assistance and impede access to entitlements.
- Establish a series of quantitative indicators and benchmarks in consultation with civil society. These benchmarks can provide measurable targets for policy as well as standards by which civil society can monitor the progress of reforms.
- It is recommended that the regulatory environment and enforcement of the Social Assistance Act and its concomitant regulations be adapted in order to comply with the tenets of administrative justice as required by the Constitution, the statutory law, and well-founded common law principles. It is further recommended that officials responsible for dealing with matters pertaining to grants, for example, when approving, turning down or reviewing applications, be made aware of the obligations on the state and the rights of applicants in this regard.

- The discriminatory elements in the provisioning of grants and insurance coverage should be removed. In particular is it recommended that the citizenship restriction for purposes of entitlement to social assistance grants be removed. All that should be required is lawful residence in South Africa.

In order to avoid further unnecessary fragmentation, it is recommended that administrative and institutional arrangements concerning people with disabilities be included in a new national framework developed for social security delivery.