

**SUMMARY OF LITERATURE:
DISABILITY and CHRONIC ILLNESS
PREVALENCE in CHILDREN
in SOUTH AFRICA**

Submitted to the
Committee of Inquiry
into a
Comprehensive Social Security System
in South Africa

Prepared by
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June 2001



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INTRODUCTION

Participants at a workshop on “research priorities for early development in Southern Africa”, held in August 2000, stressed that childhood disability was still inadequately described in the region.

Accurate statistics on prevalence rates of disability and chronic illnesses among children are essential for adequate planning of service delivery, rehabilitation programme efforts and to inform the development of a comprehensive social security system. However, there must also be concomitant emphasis on poverty alleviating strategies and the provision of basic services to poor families.

PURPOSE OF THIS DOCUMENT

The purpose of this paper is to provide some statistics for prevalence rates of disability and chronic illnesses among children. The paper also examines the relationship between HIV infection and disability. This information is to inform the macro-economic analyses when calculating the financial implications of providing social assistance to these vulnerable groups of children. The problems inherent in the prevalence statistics are also highlighted. However, it is beyond the scope of this document to examine the context of disability and incidence rate, such as the geographical, gender or racial trends and patterns, contributing and causal factors, nor the available support structures, or treatment and rehabilitation services. The Rights of the Child with Disabilities are not expanded upon here, but this has been covered extensively in document prepared by the Child Health Policy Institute and the South African Federal Council on Disability.

The information presented here was obtained from the sources indicated below:

- Adnams C. Chronic Disability And Chronic Illness In South Africa. Paper presented at the National Workshop: “Social Assistance For Children With Disabilities And Chronic Illnesses”. Cape Town. 15th & 16th May 2000.
- CASE. We Also Count: the extent of moderate and severe disability in South Africa. 1999.
- Jacqui Couper. Prevalence of Childhood Disability in Southern Africa. Prepared for the Maternal and Child Health workshop, Durban, August 2000.
- National Health & Population Development National Survey. 1996.
- STATSSA. 1996 Census.

PROBLEMS WITH DEFINITIONS AND PREVALENCE RATES OF DISABILITY

- The problems of defining disability, and the lack of clear uniform definitions have been raised repeatedly, and these directly impinge on identification, diagnosis, record-keeping and thus statistics.
- Equally problematic are the distinctions between the degrees of severity: mild, moderate and severe, and their assessment.
- Very few exact national disability prevalence statistics exist. However, it is acceptable to use the general WHO estimates, as they are relatively accurate in determining national prevalence.
- National surveys exploring *reported* disability within households usually have a higher rate than found with *confirmed* cases. This is due to subjective self-reporting of disability, as well as insensitive questionnaires (such as “who has difficulty walking to the shop?”).
- E.g. the 1996 Census which found very high rates of ‘disability’ among the elderly (over 50%) but very low among children (1.5%). This would be due to the fact that the respondents were unable to detect disabilities in the children.
- In comparison, the few small-scale studies in South Africa have found rates of disability in children between 3.3% and 6.4%. These results are comparable with other developing countries’ prevalence rates.
- It is therefore advisable to use *confirmed case* percentages from small-scale studies and extrapolate national rates from these.
- It is important to note the association between social status and disability prevalence rates. Studies¹ have confirmed that an Odds Ratio of 2.36 exists, i.e. *That the lowest social-economic families are almost two and a half times more likely to have a disabled child.*

PROBLEMS WITH DEFINITIONS AND PREVALENCE RATES OF CHRONIC ILLNESSES IN CHILDHOOD

- Very few accurate statistics for chronic illnesses in children exist.
- The rates vary widely between specific illnesses, such as 0.02% for cystic fibrosis to 13.3% for asthma.
- Each disease has widely differing prognoses, consequences and resultant needs for the child. For example, children suffering from asthma would require medication, which could be provided through indirect social security measures, such as free health care. In comparison, children with cystic fibrosis have a broader range of needs, including medical, financial and physical care.
- Rates may vary between different population groups.

¹ Natala EJ, Joseph JG, Bergen R, Thulasiraj RD, Rathmathullah L. Prevalence of childhood disability in a southern Indian city: Independent effect of small difference in social status. *International Journal of Epidemiology*. 1992;21(2):367-372.

PROBLEMS WITH ASSESSMENT TOOLS FOR DISABILITY AND CHRONIC ILLNESSES IN CHILDHOOD

- The lack of clear definitions of disability, and the difficulties of identifying differing degrees, all contribute to the inherent problems in creating sensitive, accurate and valid assessment tools.
- *There is no international validated screening tool for the under two years age group.*
- Persons with exactly the same type and severity of disability may have completely different circumstances and needs. Thus, while the medical diagnosis of the disability type and severity is important, it cannot be the only determining criteria for eligibility for social assistance.
- It must be recognised that the medical diagnosis, for accurate detection of disabilities, must be combined with a broader needs assessment, in order to develop a comprehensive social security system which addresses the holistic needs of persons.
- In assessing the needs of children with disabilities; consideration must also be given to the existing support structures and services available to the child and his/her primary care-giver. Access to public services has been proven to contribute greatly to the health of children and to the prevalence rates of disability in young children.

AVAILABLE ASSESSMENT TOOLS

- The WHO² have developed an extensive assessment tool called the ICIDH-2, now called the International Classification of Functioning, Disability and Health (ICF). The aim of this tool is to provide a unified and standard language and framework for the description of health and health-related states. The classification includes health domains and health-related domains, as well as contextual factors including environmental and personal factors. The ICF has moved away from a “consequence of disease” classification to a “components of health” classification. The environmental factors describe the context in which individuals live.
- The Child Health Unit, UCT, in collaboration with the Western Cape Department of Health developed development disability screening tools for 0-6weeks, 9months and 18months, which are administered by clinic nurses. The Child Health Unit is currently undertaking an evaluation of the effectiveness of the tools and their administration.
(For more information call: Dr Colleen Adnams/ Dr Maylene Shung-King:
Tel: 021-685-4103/4)
- Thorburn, Durkin *et al* have made great contribution to the epidemiology of childhood disability and validated a useful screening tool called the ‘ten question’ screening tool for children between 2-9 years³.

² WHO. International Classification of Functioning, Disability and Health. 2001.

³ Durkin MS, Davidson LL, Desai P, Hasan ZM, Khan N, Shrout PE *et al*. Validity of the ten-question screen for childhood disability: results from population based studies in Bangladesh, Jamaica and Pakistan. *Epidemiology*. 1994;5(3)283-289.

- The Australian social security system has a process of identifying chronic illnesses and providing beneficial scale of benefits based on need.

AVAILABLE DISABILITY STATISTICS

a. GENERAL DISABILITY FIGURES

WHO global figures:

ALL disabilities, moderate and severe = **10 – 12%** of any population.

National Health & Population Development: South African national survey 1996:

Disability prevalence = **12.8%**.

1996 Census:

Total disability = **6.6%**

NB. The Census did not include persons in institutional care, therefore excluding a large population of persons with disabilities.

CASE 1999:

Total disability = **5.9%**

b. GENERAL CHILDHOOD DISABILITY RATES

1996 Census:

Disability in children = **1.5%** (Under-reported)

CASE 1999 SURVEY:

1-5yrs = 1.6% = approximately 70 000 children

6-10yrs = 3.2% = approx 150 000 children

11-15yrs = 4.5% = approx 200 000 children

16-20yrs = 4.1% = approx 170 000 children

Average % for children under 18yrs = 3.35% = very approx 600 000 children

Small geographical South African studies among children:

Range from 33⁴ to 64⁵ per 1000 (**3.3 – 6.4%**)

⁴ Irlam J. A rural disability prevalence study in Kwazulu-Natal. Unpublished. CHU, UCT.

⁵ Kromberg JGR, Christianson AL, Manga P, Zwane ME *et al.* Intellectual disability in rural black children in the Bushbuckridge district of South Africa. *Southern African Journal of Child and Adolescent Mental Health.* 1997;9(4):2-11.

c. SPECIFIC DISABILITY-TYPES PREVALENCE RATES

Surveys: adults & children

Disability Type	1996 Census	CASE 1999
Visual	2.7%	1.7%
Physical	1.4%	
Movement activity / Moving around		2.0% / 1.7%
Daily life activities		1.8%
Hearing	1.0%	1.0%
Intellectual	0.5%	1.1%
Learning		1.2%
Emotional		1.1%
Communication		0.8%
Multiple disabilities	0.4%	
Unspecified	0.7%	
TOTAL Population with Disability	6.6%	5.9%

Small-scale South African studies in children⁶:

Severe Intellectual Disabilities	7 per 1000 ⁷ (0.7%)
Mild Intellectual Disabilities	17 per 1000 ⁸ (1.7%)
Motor disabilities	28 per 1000 ⁹ (2.8%)
Visual disabilities	14 per 1000 ¹⁰ (1.4%) (included mild & severe)
Hearing disabilities	39 per 1000 ¹¹ (3.9%) (included mild & severe)
Seizure disorders	7 per 1000 ¹² (0.7%)

NB. Certain conditions, such as cerebral palsy, cause multiple disabilities, such as motor, intellectual and/or communication.

High percentages of children with seizure disorders have an intellectual disability (43%¹³ - 68%¹⁴), as well as visual and hearing difficulties.

Hence, the total percentage of persons with disabilities is not the sum of all these prevalences.

⁶ Jacqui Couper. Prevalence of Childhood Disability in Southern Africa. Maternal and Child Health workshop, Durban, August 2000.

⁷ Kromberg JGR, Christianson AL, Manga P, Zwane ME *et al.* Intellectual disability in rural black children in the Bushbuckridge district of South Africa. *Southern African Journal of Child and Adolescent Mental Health*. 1997;9(4):2-11.

⁸ Couper J. The prevalence of childhood disabilities in the Manguza sub-district of Kwazulu-Natal, South Africa. MSc (Med) dissertation. Wits Univ. 2000.

⁹ Couper J. *ibid.*

¹⁰ Couper J. *ibid.*

¹¹ Couper J. *ibid.*

¹² Couper J. *ibid.*

¹³ Leary PM, Riordan G *et al.* Childhood secondary (symptomatic) epilepsy, seizure control & intellectual handicap in a nontropical region of South Africa. *Epilepsia*. 1999;40(8):1110-3.

¹⁴ Couper J. *ibid.*

CHRONIC ILLNESS PREVALENCE AMONG CHILDREN¹⁵

The following are the available rates of specific illnesses in children. Lack of accurate diagnosis and recording contribute to the problems in the available statistics.

HIV/AIDS: There are between 60 000 and 100 000¹⁶ HIV+ children born *each year* in South Africa.

Asthma: 13.3%¹⁷

Congenital heart disease: 7 per 1000 (0.7%)

Acute Lymphocytic Leukaemia: 0.25 per 1000 (0.025%)

Cystic fibrosis: 0.2 per 1000 (0.02%)

Diabetes & Epilepsy: it is impossible to get national statistics, but trends show drastic increases in incidence over the last few years. This may be partly due to the increased access of the majority of the population to basic health care services, where accurate diagnosis is occurring. Changing patterns of life-style and nutrition may contribute to the increase in diabetes.

More detailed information has been collected on chronic diseases in childhood by Dr.Colleen Adnams. This could be made accessible to the Committee of Inquiry, with permission.

THE ASSOCIATION BETWEEN HIV/AIDS AND DISABILITY

IN CHILDREN IN SOUTH AFRICA

The majority of children under the age of 13 years acquire HIV from their infected mothers during pregnancy, at the time of delivery or after birth, through breastfeeding. This is termed Mother-to-Child Transmission (MTCT).

In children the progression of HIV infection to AIDS is extremely rapid. 60% of the children infected through MTCT will not live beyond their 5th birthday¹⁸.

The provision of Anti-retroviral treatment for pregnant HIV+ women would reduce the numbers of children born with HIV infection by 50%. This would greatly reduce the numbers of children requiring social assistance and the huge hospital and medical costs.

¹⁵ Adnams C. Chronic Disability And Chronic Illness In South Africa. Paper presented at the National Workshop: "Social Assistance For Children With Disabilities And Chronic Illnesses". May 2000.

¹⁶ IDASA. Child Poverty and the Budget 2000. IDASA's Budget Information Service. 2000.

¹⁷ International Study on Allergy & Asthma in children. 1999.

¹⁸ Giese S. The Impact of HIV/AIDS on the Health and Welfare of Children in South Africa and on health and welfare Services for children. Prepared for HEARD, Durban. 2001.

Poor prognoses and increased speed of progression are associated with malnutrition, higher viral load, increased virulence of the virus, poor nutritional status of the child, concurrent infections (such as measles or TB) and lower economic status.

Thus good nutrition, adequate public services (water & electricity) and appropriate medication (including drugs to prevent MTCT and opportunistic infections, as well as Anti-Retroviral Treatment) would greatly reduce the child's chances of dying, and enhance their health and well-being¹⁹.

RECOMMENDATIONS

A comprehensive social security system must include cash transfers, as well as indirect social security benefits. Free medication, rehabilitation, transport, food vouchers, electricity and water supplies would greatly assist the child with a disability or chronic illness.

It is advisable to use *confirmed case* percentages from small-scale studies and extrapolate national rates from these.

It is suggested that an average overall rate for childhood disability of approximately 3-4% be utilised for planning and budgeting purposes. Approximately 1% of children could be considered to be HIV+. The numbers of children with other chronic illnesses are so small that they could easily be absorbed into the current system.

The existing Care Dependency Grant should be extended to children with moderate disabilities and chronic illnesses, including HIV/AIDS.

Eligibility to social assistance for children infected with HIV (such as the Care Dependency Grant) must be immediately upon diagnosis of HIV infection. *Waiting until the child reaches the final stages would fail to enhance and lengthen his/her life. In addition, the chances are that the child would be dead before the application had been processed and approved.*

It is therefore necessary to introduce measures for HIV+ children to be fast-tracked within the social security and social support systems.

It is recommended that a Needs-based approach to assessment be adopted, which considers the holistic situation and the needs of the individual, including social, financial, health, practical, as well as considering what services are available to him/her, such as free medication from State hospitals and rehabilitation services.

¹⁹ Piwoz E, Preble E. HIV/AIDS & Nutrition – a review of the literature and recommendations for nutritional care and support in SA. Academy for Educational Development.

Examination of the ICIDH-2 (ICF) tool, the Ten Question Tool, and the Child Health Unit's screening tool might provide useful guidelines for the development of the Needs-Based assessment tool.

CONCLUSION

Social security should provide for the basic needs of a child, and for those special needs that arise from a chronic health condition (including disabilities and HIV infection), or from a compromised home situation, in order to ensure his/her survival and a standard of living adequate for his/her development.

Children with moderate and severe disabilities and chronic illnesses, including HIV/AIDS, form a particularly vulnerable group within our society. These children have the Constitutional right to benefit from Social Security and Social Assistance.

Providing assistance in the form of cash transfers and access to social, health and public services would greatly enhance and extend the lives of these children.

Concurrent programmes aimed at poverty alleviation and development at community levels would also reduce the risk of infection and disability.

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