

# Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults

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## Purpose of review

This review aims to summarize data published in the scientific literature and available on official websites on the epidemiology, policies and services for children and adults with intellectual disability in South Africa.

## Recent findings

There is a paucity of published literature on intellectual disability in South Africa. The lack of evidence-based publications within the prescribed review period of 12–18 months precludes an accurate description of the prevailing epidemiology and burden of disablement in this country. The few studies yielding epidemiological data were conducted prior to 2002. These suggest that the prevalence rate of intellectual disability is greater than in high-income countries. There is little data describing intellectual disability geographically and across population and age groups, further rendering it difficult to identify inequalities and differences in distribution. There is a high burden of preventable causes of intellectual disability.

## Summary

Despite the existence of policies and services for the population with intellectual disabilities in South Africa, recognition of and provision for their needs carries low priority. It is imperative that the information gap in epidemiology and the burden of disability be recognized in order to plan for and meet the needs of those with intellectual disability across the lifespan.

## Keywords

epidemiology, intellectual disability, policy, services, South Africa

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## Introduction

South Africa has a population of approximately 49 million and is classified as an upper middle-income country. In terms of income and available resources, there is a large gap between the small, but growing, middle class and the poor majority, who, after 16 years of political democracy, remain defined by the legacies of inequality of the apartheid era. Within this context, people with intellectual disabilities (PWID) in South Africa mirror this inequity and are to be found amongst the poorest, most vulnerable and marginalized.

The literature search for this review included Medline and official websites of governmental departments, non-profit organizations and South African medical and human science research institutes. Because there were so few publications in the period under review (12–18 months), in particular epidemiological studies on intellectual disability, the search was extended to cover published data and online content from 2002 onwards, with a

focus on the last 2–3 years. Key search words included intellectual disability, epidemiology, prevalence, policy, and services, South Africa.

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## Epidemiology

Although intellectual disability is the official term used in South Africa, a wide variation in understanding and lack of agreement on definitions and terminologies has contributed to problems in accurate collection and interpretation of epidemiological data [1].

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## Prevalence

Three nationwide studies have attempted to describe the epidemiology of intellectual disability. In 1999, the first National Disability Survey [2] yielded prevalence for all disabilities of 5.9% and that of intellectual disability of 1.1%. A second study [3] was conducted as part of the national census survey in 2001. The prevalence of intellectual disability was 0.5% and overall disability

prevalence was 5.0%. Of the population with disability surveyed, only 30% had any formal education. The census did not include persons in institutional care, therefore excluding a large population of persons with disabilities. In 2007, a further national survey [4], which examined severe intellectual or learning disability, yielded a prevalence of 0.27%. The methodology in all these studies involved regional household surveys about the existence and experience of disability.

Other smaller South African studies focused on localized populations of children. Couper [5] used the internationally validated ten questions screen for childhood disability in developing countries [6] to screen 2036 children aged 2–9 years in a rural area. On the basis of the screen, the study reported a prevalence rate of 1.7% for mild perceptual or learning disability. This figure could be lower than expected due to the failure to recognize mild intellectual and learning difficulties in young children. In a study in eight villages in another rural area, Kromberg *et al.* [7] screened a total of 6692 children of 2–9 years with the same ten questions tool on a house-to-house basis, and in a second phase the 722 children (10.8%) who screened positive were clinically examined and assessed neurodevelopmentally by a paediatrician. Overall, 4.3% of the children had one or more of five disabilities (intellectual, visual, hearing, movement disorder or epilepsy). Intellectual disability occurred in 3.6% of the children. The prevalence of mild [general intelligence quotient (GIQ) 56–80] and severe (GIQ <56) intellectual disability was 2.9 and 0.64% respectively. There was a male predominance of intellectual disability (ratio 3:2). The use of the same screening tool in both studies demonstrates the variability in reported versus confirmed data.

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### Causes of intellectual disability

No reliable data on the cause of intellectual disability in South Africa exists. Clinic derived reports suggest that a number of causes of intellectual disability in South Africa have a similar prevalence to developed countries. A few studies have examined cause in small population samples. Kromberg *et al.* [7] reported a congenital cause in 20.6% of affected children, an acquired cause in 6.3%, and in 73.1% the cause was undetermined.

In terms of environmental factors, there is evidence for an association of poverty and intellectual disability [8], including in the world's richer countries [9], but, as in other developing countries, in South Africa there is little data on the mechanisms through which poverty and disability affect each other.

High prevalence rates in South Africa for conditions that are associated with onset of intellectual disability in the prenatal and developmental period would suggest a

higher total prevalence of intellectual disability than in developed countries. Most of these conditions are preventable, and this fact underscores the need for accurate epidemiological data in order to address effective interventions to reduce the prevalence of conditions that contribute to intellectual disabilities in South Africa. Conditions that impact on the burden of disability, through either a high prevalence or severity, include nutritional deficiencies, infectious diseases, including mother-to-child transmitted HIV/AIDS and tuberculous meningitis (TBM), fetal alcohol spectrum disorder (FASD) and violence and injury.

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### Nutritional deficiencies and growth stunting

As indicators of poor development, nutritional deficiencies and growth stunting represent multiple biological and psychosocial risks. Childhood undernutrition is generally associated with concurrent and long-term global deficits in cognition, behaviour and motor skills, although the relationship is likely to be confounded by socioeconomic factors [10]. Mostly, the resultant cognitive disorder is mild intellectual disability with or without specific learning difficulties. There is a strong and consistent relationship of growth stunting and poor child development with moderate-to-large effects, and early childhood stunting has been shown to be a good predictor of poor school achievement and cognition in 7-year-old South African children [11].

In a 2000 study estimating the burden of disease of underweight and protein–energy malnutrition (PEM) in South African children less than 5 years old [12], 11.8% of children were reported to be underweight – an improvement over reports from previous years. Apart from contributing to child mortality, PEM contributed 44.7% of the total attributable burden of physical disease, implying a further burden of illness owing to undernutrition in children with intellectual deficits. Because of the increase in paediatric HIV/AIDS in South Africa in the last decade, PEM has reemerged, a complication of this epidemic. Thus, for present time relevance, this review includes a historical report of a 20-year follow-up of 20 South African children with severe PEM in infancy, who presented with significantly reduced head growth, structural brain changes, lower cognitive performance and poor scholastic achievement (mild intellectual disability), problems with social adjustment and unemployment in early adulthood [13].

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### Neuro-AIDS

South Africa is severely affected by the HIV/AIDS epidemic, with both the highest reported prevalence of HIV/AIDS per capita and the world's largest population (over 15% of the population aged 15–49 years and 280 000

children 0–14 years old) living with HIV. Joint United Nations Programme on HIV/AIDS estimated that in 2009 the total number of persons living with HIV in South Africa was 5.7 million [14]. Ninety-five percent of children infected with HIV in sub-Saharan Africa (SSA) acquire infection from their mothers. HIV/AIDS is a leading cause of death in South African children under 5 years. Children in SSA, including South Africa, who survive without early treatment have a high prevalence of cognitive disability, visual spatial and motor deficits [15,16], as well as neurological impairment, seizures and encephalopathy [17]. A study by Smith *et al.* [18] demonstrated the significant effect of vertically transmitted HIV/AIDS on the development of children, even when treated. The children, who met criteria for treatment with highly active retroviral therapy, functioned in the mild intellectual disability range for verbal and nonverbal performance despite treatment. Although treatment to prevent vertical transmission of HIV is increasingly being made available during pregnancy to HIV positive women in South Africa, many thousands of older children remain HIV positive. The actual rate of intellectual disability in children with vertically transmitted HIV in South Africa is not known, but it is likely significant. Because of their parents' illness and the possibility of being orphaned (there are 1.5 million HIV/AIDS orphans in South Africa [14]), the likelihood of accessing appropriate interventions for intellectual disability is diminished and the double burden of being orphaned and intellectually disabled places the children at further risk of compromised development.

Although cognitive deficits acquired beyond the developmental period do not fall within the definition of intellectual disability, in adults, HIV-neurocognitive impairment and, more severely, HIV-dementia are major and common complications of HIV disease. HIV-associated neurocognitive disorders (HAND) occur globally and across different genetic clades of the virus, and these cognitive manifestations of HIV encephalopathy are increasingly being recognized as placing a considerable burden on intellectual functioning of high numbers of adults infected with HIV. Joska *et al.* [19] reported a prevalence of 23.5% of HAND in an adult clinic cohort in South Africa. At a national level this translates to many thousands of adults whose cognitive skills loss impacts further negatively on the burden already carried by the poorest of the population – that of poor educational attainment, low work skills base and high unemployment.

Furthermore, given the high prevalence of HIV in South Africa and the risk of PWID for abuse and exploitation, it can be expected that a large number of PWID in South Africa are infected with HIV. The prevalence of HIV/AIDS in the disabled population is estimated to be 14% [14]. This raises important considerations for appropriate

HIV testing counselling and life skills support, as well as provision of adequate healthcare in PWID who are infected with HIV.

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### **Tuberculous meningitis**

There is a high incidence of tuberculosis (TB) in the Western Cape region of South Africa [20]. TBM is the most severe form of extrapulmonary tuberculosis and is associated with high morbidity and mortality rates, especially in younger children. Children with a poor outcome develop severe neurological and multiple disabilities. HIV coinfection increases the risk of developing TBM with a higher rate of complications. Hydrocephalus, a common complication of TBM, may be associated with a poor cognitive outcome if treatment is delayed. TBM is an important cause of moderate and severe intellectual disability in young South Africans.

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### **Fetal alcohol spectrum disorders**

The burden of mental and physical disease associated with high levels of alcohol abuse in South Africa has major implications for intellectual and cognitive disabilities. FASD results from prenatal alcohol exposure owing to excessive maternal drinking. In high-risk regions in South Africa, the prevalence rates of FASD, of which fetal alcohol syndrome (FAS) is the most severe expression of the spectrum, are the highest in the Western world. Urban *et al.* [21] reported a prevalence of 6.7% in grade 1 children of the full features of FAS in one provincial area and May *et al.* [22] described a prevalence of FAS and partial FAS of 6.8–8.9% in similarly aged children in another high-risk region. The majority of children and adults in South Africa with FASD function in the mild intellectual disability range and demonstrate associated executive function, social and behavioural difficulties. FASD is a major public health problem in South Africa and places a burden on a number of systems, including health, education, social services, labour and criminal justice, at both fiscal and societal cost.

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### **Violence and injury**

In South Africa violence and injury carry a high burden of morbidity and mortality [23\*\*].

Traumatic brain injury (TBI) contributes significantly to this burden. TBI is an important preventable cause of intellectual disability in children across the developmental span and also of cognitive impairments in older adolescents and adults. The road traffic death rate is amongst the highest in the world (33.2 per 100 000 population) [24]. Morbidity for survivors of road traffic accidents is estimated at 20-fold higher than the rate of fatality, suggesting a high burden of disablement of TBI.

In a report of 37 610 children with head injuries treated at a paediatric tertiary hospital in Cape Town between 1991 and 2001, over one-third of children were injured in road traffic accidents and physical assaults [25]. Almost two-thirds of the children involved in road traffic accidents were pedestrians. Of the survivors of head injuries of all causes, 17.9% of children had moderate or severe head injuries. Alcohol plays a significant role in the epidemiology of TBI, both in children and adults who may be victims of violence and motor vehicle accidents.

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### Comorbidity

In children with intellectual disability, the commonest associated neurological conditions were epilepsy (15.5%) and cerebral palsy (8.4%) [7]. The same study reported 0.7% of children screened for developmental disability had epilepsy, and of those with a seizure disorder a high percentage (71%) had an intellectual disability.

There is little published information on mental disorders in PWID in South Africa. Given the increased risk for mental illness in PWID and the high prevalence of mental disorder described in the general population [26], this is a neglected area.

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### Policies for children and adults

In contrast to many African countries [27], numerous South African policies address disabilities, including intellectual disability. The rights-based South African Constitution makes provision for PWID and South Africa is a signatory to the United Nations Convention of the rights of persons with disabilities and the United Nations Convention of the rights of the child. Within the relevant sectors, policies make provision for social security (disability) grants for children and adults, health security in the form of free primary healthcare for grant recipients and fiscal or tax benefits. Uptake of disability grants has considerably increased in recent years, but many still do not access this benefit. There is a health policy on rehabilitation and interventions, and the National Mental Healthcare Act addresses the rights of mental healthcare users, including users with intellectual disability. In line with developed countries, a national strategy for the deinstitutionalization of PWID from long-term stay state hospitals has been implemented. Within education, policies provide for inclusion of learners in the mainstream system and also for specialized educational support.

In reality, in spite of existing policies for PWID, with few exceptions, low prioritization, budget, and resource commitment through all levels of government has resulted in few of the policies being effectively implemented. In South Africa, poverty and inequality have racial, sex and spatial dimensions and Black African women and youth in

rural areas remain the most marginalized. In addition, as in many African countries [28], disability is traditionally stigmatized in South Africa and women largely take responsibility for the care of children and adults with intellectual disability.

Limited national strategies for the prevention of intellectual disability may include genetic counselling programmes and some prenatal screening.

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### Services for children and adults

In line with policies, a range of services for PWID is outlined by government sectors, but a comprehensive and integrated approach is often hampered by a lack of prioritization of resources and intersectoral coordination. In many areas, basic and other services are provided by the nongovernmental sector. Services tend to be concentrated in larger centres and many PWID in rural areas have no meaningful access to services at all.

In each province, special schools provide for school-aged learners with a range of developmental disabilities. Education policies have not been implemented for those with severe and profound intellectual disabilities, and in practice this group is excluded from governmental educational benefits. Within the mainstream education system, although national policy provides for learners' special needs, those with mild intellectual disability in general do not have their learning needs adequately met within a system still struggling with a legacy of inequity inherited from the apartheid era.

Specialized health services, including mental health services for PWID, are few and largely focused in secondary and tertiary centres in towns and cities. In all regions, in spite of policy for rehabilitation, there is inadequate provision for multidisciplinary health services for PWID.

Throughout the country, there are major service gaps for adolescents and adults with intellectual disability. The gap extends to published literature on services for PWID other than organizational reports.

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### Conclusion

In spite of commendable progress in policy and legislation development and numerous governmental and nongovernmental good practices, South Africa has yet to reverse the marked inequities in human rights and access to care and services that prevail for large numbers of disadvantaged PWID. Failures in policy implementation and service delivery, and the low priority of intellectual disability, continue to result in unmet social, health and educational needs. In addition, the overall burden of disablement of intellectual disability by preventable causes is both a cause

for concern and a call for action to government and civil society.

Against a background of rapid changes in the country's health, economic and sociopolitical profile during the last decade, it is imperative that legitimate national data and further research provide the basis for development of evidence-based practices and strategies for the benefit of this vulnerable population.

## References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 485).

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