

Intellectual Disability in South Africa

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Statistics

There is no certainty as to the number in of people with intellectual disabilities (PWID) in South Africa. Although regular population censuses have been held and questions have regularly been asked about disability there has been an inconsistency in the questioning and changes to terminology and classifications made over time that have muddled the process. Various attempts have been made to estimate the extent of disability but even recent government research from various departments contradicts itself (including the recently produced Baseline Country Report to the United Nations on the Convention of the Rights of Persons with Disabilities in South Africa)¹.

Although the current terminology is intellectual disability there is still a wide range of terms in common use and this lack of commonality of definition contributes to the problems of accurate data collection and reporting.

In 1996 disability was estimated at 6.95% of the population (of a total of 40 million).² In that year the census question on disability was “Does the person have a serious sight, hearing, physical or mental disability? If yes, circle all applicable disabilities for the person: Sight 1; Hearing/Speech 2; Physical disability 3; Mental disability 4.” In comparison, the disability question posed in the 2001 census read: “Does the person have any serious disability that prevents his/her full participation in life activities? None 0; Sight 1; Hearing 2; Communication 3; Physical 4; Intellectual 5; Emotional 6.’

The Census of 2001³ indicated that there were 2,255,982 people with various forms of disability in South Africa (from a population of 45 million). This number constituted 5% of the total population enumerated in that census. Of this number, 1,854,376 were African, 168,678 coloured, 41,235 Indian/Asian and 191,693 white. The number of females affected was 1,173,939, compared to 1,082,043 males. Of the total with disabilities 12% were categorised as having an intellectual disability. The 2001 census indicated that 702, 011 individuals between

the ages 15 and 65 were unemployed due to illness and disability. It also indicated that a significantly high 99.28% of the disabled that are employable, are unemployed and that 33% had received no schooling at all. However the census failed to take into account people who were living in institutional care.

In 2007 South Africa carried out a Community Survey of 274,348 households.⁴ This found that the percentage of persons having disabilities had decreased from 6.5% in 1996 to 4% in 2007. The Indian or Asian population group had the highest percentage of persons with disabilities (4.6%). The most prevalent disability was physical disability at 1.6%. During the Community Survey 2007, the disability question was split into three distinct questions and respondents were asked whether they had any kind of disability; if they had, the type of disability; and the intensity of the disability (that is, whether the disability seriously prevents the person from full participation in life activities such as education, work, social life, etc). Type of disability was split between sight; hearing; physical; mental; multiple and unspecified. Total mental disability of 128,841 was recorded against an estimated population of 48,502,064.

The classifications used in these censuses and surveys were based on the World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH)⁵; which defined it as a physical or mental handicap which has lasted for six months or more, or is expected to last at least six months, which prevents the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities. Societies thinking at this point was that it was often an inability to do tasks that caused a person to become socially handicapped and largely excluded from society as a whole. Therefore the solution was to work with the individual to overcome their problem, the problem was not that of societies attitudes and the way that they see peoples differences.

This definition was changed for the Census of 2011. Disability was defined using the Washington Group method which evaluates difficulties encountered in functioning due to body impairments or activity limitation, with or without the use of assistive devices. The questions relate to difficulties people have in executing a series of activities; seeing, hearing, walking,

communicating, and self-care, remembering and concentrating. In regards to the question on remembering and concentrating 95% replied that they had no problems, whilst 96.65% reported no problems with self care. The 2011 census estimated the total population of South Africa at 51.7 million.

The lack of reliable statistics impacts on the ability of government to make accurate social policy decisions regarding disabled persons. In addition, historically, disability issues were always looked at only in the context of a health and welfare framework. This has led to the failure to integrate disability into mainstream government statistical processes as highlighted in the 1997 Integrated National Disability Strategy⁶ which set out the need for government departments to evaluate the needs and challenges and to integrate these into policies, programmes, plans and procedures. This failure to look at the situation holistically also impacts on the provision of adequate funding to meet the needs of disability groups.

Statistics and information relating to the causes of ID are similarly unreliable. Whilst South Africa is a middle income country it has the greatest inequality in the world. Malnutrition, poor education, lack of access to adequate health care facilities all impact on the incidence of ID. Poor prenatal care can cause ID, in particular poor nutrition, iodine deficiency and Fetal Alcohol syndrome (FAS). These incidences of prenatal causes are all preventable. Whilst intellectual disability has an estimated prevalence of between 2% and 3% in developed countries a study in rural areas of South Africa found a prevalence rate of 3.6%.⁷

It is estimated that at least one million people in South Africa have fetal alcohol syndrome and approximately five million have partial foetal alcohol syndrome and [other] fetal alcohol spectrum disorders.⁸ “Fetal alcohol spectrum disorder is the most common birth defect in South Africa, easily more common than Down syndrome and neural-tube defects combined. FAS is the most common cause of ID and is particularly high in the Western Cape. The Western Cape government is working on programs to identify mothers at risk and to diagnose children as early as possible. In addition to conducting awareness, educational and prevention interventions there are programmes in place to identify, recruit, train and equip health workers, educators,

professionals and other community volunteers to implement an awareness and education programme in at-risk communities. These aim to equip women in their childbearing years, especially those at risk, to make informed choices, enabling them to protect their unborn babies from the devastating effects of alcohol consumption during pregnancy and, in so doing, to reduce and prevent alcohol related birth defects. Despite this it is believed that the incidence of FAS is substantially under reported. Nor is FAS restricted to viticulture areas of the Western Cape. A recent study in Aurora in the Western Cape diagnosed a FAS rate of 10% with another 7% for partial FAS.⁹

In addition to the lack of reliable statistics 'there is a paucity of published literature on ID in South Africa. The lack of evidence based publicationsprecludes an accurate description of the prevailing epidemiology and burden of disablement in this country'.¹⁰

South Africa and the Disability Rights Movement

Disabled people in South Africa have effectively suffered apartheid twice. Once under the political system that divided the races and secondly under an unwritten system that segregated the disabled from the able bodied. In the 1970's and the 1980's all disabled people were largely treated as helpless and few facilities were put in place to allow people to develop, grow or even to go about their daily lives with any sense of dignity. As a result they were largely excluded from education and employment and were generally invisible to society. Those who had a severe disability, be it physical or intellectual, were housed in hospitals or asylums and kept largely within the confines of the institution in which they were housed.

The disability rights movement in South Africa can be traced back to 1981 with the UN Year of Disabled Persons. Although this was not recognised by the government of the time it was promoted by many disability NGO's. By 1984 a group of people had set up Disabled People South Africa (DPSA), run by disabled people for disabled people and it has shaped South Africa's policies towards disabilities over the intervening years. Its beginning was a response to the fact that any commission of inquiry or any government body that looked at disability issues never seemed to have persons with disabilities as part of the panel. It was always people without disabilities talking to people with disabilities. There was also interaction between white

and black people with disabilities for the first time. To be black and disabled at this time was to be totally marginalised. The state offered a deliberately substandard level of schooling for non whites, alongside poor or non-existent medical and rehabilitation facilities. Various groups started to get together to work towards a better environment and better conditions. One of these groups was the Self Help Group of Paraplegics in Soweto, or SHAP as it was more commonly known. Many of these groups were formed around specific disabilities, but DPSA was different as its members were drawn from all disability groupings. Their strategy was to build local groupings to work towards better conditions for all types of disability. By 1986 when the government had decided to recognise a year of disabilities the DPSA was sufficiently well organised to be awarded a government grant which was used towards the purchasing of assistive devices. Gradually membership increased and the group attracted some funding from abroad to continue its advocacy efforts and by 1992 the Disability Rights Charter was established which lobbied for independent living in a safe environment free from discrimination.

The DPSA was also unusual in that it demanded gender parity in its representation, there was an acknowledgment that disabled women were the most marginalised group and firm efforts were made to counter this. Each local group was always headed by a man and a woman. Despite this even in 2001 it was acknowledged that the visibility of women as leaders within the organisation was still very low. As democracy dawned the DPSA was active in working in incorporating disability rights into the new constitution. For all that the constitution speak to equal rights within South Africa, as with the rest of the continent, disability is stigmatized with women bearing the brunt of the caring for PWID.

There were a number of NGO's active in the disability arena at the same time and these formed an umbrella body the South African Federal Council on Disability which together with DPSA worked on developing disability rights and providing services to the disabled community on behalf of and in conjunction of the government.

The Western Cape Forum for Intellectual Disability has been running for over 40 years. Established by Doctor Vera Grover in 1970 it was founded to develop services at a regional

level for all those in the Western Cape with a mental retardation (the term in use at the time) and was funded by a grant from the South African National Council of Mental Health. In 1986 the term mental retardation was changed to mental handicap and from this to the term intellectual disability in 2000. Advocacy work for service providers in the field, along with mutual support, training and research were the founding aims. The forum now represents 150 organisations and individuals. Over the years they have successfully lobbied for an increase in provision of care grants for those over the age of 18 needing care, increasing subsidies for protective workshops and successfully won the right to education for those with a profound intellectual disability. They fill a gap in service provision with on-site training at 16 special care centres from previously disadvantaged communities. This covers everything from financial management, programme development, governance, physiotherapy, communication and information about HIV/AIDs and TB. They also produce pamphlets, DVD's, booklets specifically developed for PWID. As well as advocating for the care of those with PWID they seek to ensure that the rights and needs of PWID are incorporated in government policies, provide opportunities for skills development and speak for those unable to speak for themselves. They also award scholarships for research and resource development in the field.

Government policy - general

The UN declared 1981 as the International Year of Disabled Persons but this was ignored by the South African government. This was followed by the UN Decade of Disabled Persons from 1983 to 1993. The South African government recognised 1986 as the National Year of Disabled Persons (that year was the UN Year of Peace which the SA government did not recognise). This focus of attention on disability issues led to the recognisance that there was no disability policy in place and that the services offered by government were both few and far between and largely inadequate. As a result the government set up an Interdepartmental Co-ordinating Committee for the Care of the Disabled. This was a collaboration between the NGO sector and the state.

By 1991 none of the recommendations had been implemented and the committee was disbanded. A new organisation, the South African Federal Council on the Rehabilitation of Disabled Persons, was formed in its place. This organisation also struggled to be effective but in

1993 the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities gave guidelines that governments could work towards. One of the key aims was to work towards equalisation of opportunities for people with disabilities through the enactment of policies and the working together of state and NGO's. Another key step forward in the process was the adoption of the new constitution of South Africa in 1996. It serves to protect and promote the rights of people with respect to equality and with respect to human dignity. Affirmative action is provided for. These rights are contained in the Bill of Rights.¹¹ In addition the Constitution provided for the Employment Equity Act and for the Labour Relations Act.

The Employment Equity Act, 1998 (EEA) aims to eliminate unfair discrimination in the workplace. Through affirmative action it aims to redress past disadvantages suffered by workers. The designated groups are blacks, women, and people with disabilities. The EEA defines disabled people as "people who have a long-term or recurring physical or mental impairment, which substantially limits their prospects of entry into, or advancement in, employment." In terms of the EEA, employers may not unfairly discriminate against employees or applicants for employment because the employer suspects or believes, whether the belief or suspicion is correct or not, that the applicant or employee has an impairment that amounts to a disability, or that they have been disabled, or they are, or have been, associated with other people who are, or have been, disabled.

By 1995 a disability desk had been established in the Presidents Office as part of the RDP programme, this led to the Office of the Status of Disabled Persons in May 1997 with the broad aim of ensuring that disability issues were addressed by all governmental offices.

The Office on the Status of People with Disabilities (previously the Disability Unit) was established in 1997 as a Directorate of the Office of the President, with the aim mainly to influence policy development and to start to change the attitudes of society towards disability. This brought together various government departments (housing, health, labour, environment, welfare, transport etc) to work on disability issues noting that, at the time, the majority of disabled people were excluded from society and that less than 1% were in formal employment.

In 2009 the Office on the Status of People with disabilities was moved to the Department of Women, Children and People with Disabilities.

The Integrated National Disability Strategy of 1997 worked towards the development of policies and programmes aimed at people with disabilities. These included free healthcare, social assistance and inclusive education for both adults and children. The strategy, noted in particular that women were still seen as second class citizens and as a result were more likely to be malnourished, destitute, illiterate with lesser chance of founding a family. The strategy also acknowledged the change worldwide to reposition disability as a human rights issue (rather than health and welfare) arising from the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The strategy stressed the need for further research into promoting the participation of people with disabilities in society. Disability was starting to be seen as coming from the environment in which a person found themselves rather than being located within the person themselves.

The National Disability Strategy comments on the vulnerability of PWID in the move from institutional care to living in the community and that unless the proper levels of assistance are put in place they often end up homeless and living on the streets. In addition it notes the poor medical and services infrastructure in place to help PWID. "People with severe intellectual disabilities living in rural areas often have a low life expectancy, due to lack of care, support and access even to the most basic services. Families can seldom meet the additional financial burden of regular visits to hospitals, additional expenses for equipment and assistive devices, and other necessities".¹² South African researchers at this time were also keen to stress that much of the available material and research in this area emanated from the West and some of the solutions proposed were therefore not appropriate to the African context. Acknowledgment of the needs for different approaches for diverse cultures are largely missing from the Western approach.

South Africa celebrates National Disability Rights Awareness Month annually between 3 November and 3 December. The 3rd of December is the International Day of persons with

Disabilities which is also known as Disability Rights Day. The South African Government, led by the Department of Women, Children and People with Disability runs a comprehensive campaign to raise awareness on key issues affecting disabled people. During the Disability Rights Awareness Month, government works to inform people of the barriers that stop PWD from being fully integrated into society. The educational aspect aims to change attitudes towards PWD and to look at ways that the government has worked to better the lives of those affected.

PWID are vulnerable and South Africa suffers from persistently high rates of rape and sexual abuse. In the early 1990s Cape Mental Health established the Sexual Assault Victim Empowerment (SAVE) programme. This provides assessment, support and court preparation services for PWID who have been the victims of sexual assault, by assisting them with investigation and evaluation of their competence to act as witnesses or their capacity to consent to sexual intercourse, compilation of court reports, and provision of expert evidence in court. The programme has trained many members of the South African Police Services and public prosecutors to develop the skills they need to conduct interviews with PWID with greater sensitivity and understanding of their special needs.

Despite these efforts PWID remain marginalised, policies look good on paper but achieving the necessary changes and support has proved difficult. In addition “ Implementation of the CRPD in rural areas has been particularly deficient due to the compounded impact of traditional beliefs, poverty, low literacy levels and lack of access to the built environment, ICT and transport infrastructure that persons with disabilities and their families living in rural areas have to endure.¹³ There is no obvious co-ordination of policies that will look after PWID throughout their life. For many their lives remain in the shadows and they are only seen when they take up a health service. Access to services varies hugely by province. In the Western Cape there are an estimated 180,000 PWID of varying levels. Of these only about 2% have a place at specialised day care or in a protective workshop.¹⁴

Disability and Employment

The UN Convention on the Rights of Persons with Disabilities (CRPD)¹⁵ specifies that State Parties “shall safeguard and promote the realisation of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia, employ persons with disabilities in the public sector”. The South African government then set a target of having 2%¹⁶ of people employed in the Public Service to be disabled persons. This target was set in November 1995, when the first White Paper on the Transformation of the Public Service identified a 2% disability equity target with a deadline of ten years. By April 2005, the reported percentage of employees with disabilities in the Public Service was only 0.15%. The deadline for this target has since been extended twice; first to March 2010 and most recently to 2014.

According to the Public Service, the percentage of employees with disabilities in the Public Service as at October 2007¹⁷ - was a mere 0.2%, requiring at that time a further 19,823 people with disabilities to be employed in order to reach the 2% disability equity target. At the end of the 2010 Financial Year the Department of Public Works stated the percentage of people with disabilities employed by Government was a mere 0.22% which had increased to 0.36% in 2012. In 2013 the South African government became the biggest employer in the country, employing 22.6% of the total workforce.

In 2007 the Department of Public Service and Administration published a handbook ‘Reasonable Accommodation for People with Disabilities in the Public Service’ followed in 2012 by a policy on accommodation and assistive devices. Despite these efforts only 50,867 disabled persons out of the total work force were reported to be in employment in both the private and public sector in 2013.¹⁸ This is despite substantial efforts made by government to increase these figures. A training course in disability management developed in 2011 by the Public Administration Leadership and Management Academy in order to provide officials with skills that would assist them with inclusion of persons with disabilities in the workplace, and remove barriers preventing their successful participation in the job market. Between October 2011 and 31 March 2013 574 officials have been trained. 293.4. A database has also been created of

persons with disabilities in order to assist in recruitment persons for employment in the Public Service.

In the private sector persons with disabilities accounted for approximately 0,8% (43,666) of the total number of employees by all employers in 2011/12, down from 0.83% (43,913) in 2010/11; more than 60% of employees with disabilities occupied semi-skilled, unskilled or temporary positions in 2011/12.¹⁹ No data split of type of disability is available.

According to the Baseline Country Report to the Convention on the Rights of Persons with Disabilities 9,541 persons with disabilities were enrolled in learning programmes between 2008 and 2011. Of these 5142 finished their learnerships and went on to gain employment. There is no breakdown of type of disability given.

Throughout the country there are protected workshops for disabled people. In 2012 the Department of Social Development subsidised 293 protective workshops across the country. Managed by organisations for persons with disabilities, these employed 14,212 persons with disabilities. There are plans to increase these and to make them more accessible. In particular, there are few facilities in rural areas and provincial governments aims to remedy this. These are to be expanded to include entrepreneurship, training and skills development. In the Western Cape this forms part of the core Persons with Disabilities Programme.²⁰ Despite this, protective workshops are far and few between, the Western Cape is only opening one new workshop in 2014-2015 in Mitchells Plain and this is specifically for youth with intellectual disabilities. In the Northern Cape in 2013-2014 R750,000 was set aside for the funding of two Protective Workshops, R2.8 million to homes for people with disabilities and R1.3 million will be channeled via NPO's who offer services to people with disabilities. Whilst the government does provide some funding for protective workshops, either through the Department of Health or the Department of Social Development, often this funding is only a grant until someone reaches the age of 21 after that there is no funding available.

The Department of Social Development is working with the South African Federation of Mental Health (SAFMH) on the development of a best practice model for protective workshops, part of which is to make the workshops more sustainable. In 2013-2014 there will be specific training of managers of protective workshops in the Gauteng area in how to run this best practice model. The government, with funding from the Department of Health and the Department of Social Development, funds awareness of mental health (including ID) issues and to strengthen capacity building. Corporate sponsors are also involved in these initiatives.

As an example the South African Federation of Mental Health 2013 best practice model for protective workshops is based on 6 levels of skills and aims to equip people with mental health issues and or intellectual disabilities with the skills to enable them to participate in the open labour market. It also runs training programs in township care homes for children with intellectual disabilities. This looks to both increase the skills base of the carers but also to integrate PWID into the community and to teach basic work skills with the aim of eventual employment. The funding for this comes from both the private sector and government. There are also partnerships with private companies who take on suitable candidates for the workshops and work within the new guidelines.

Of the residential homes in the Western Cape only a few have work training facilities or workshops. Cape Mental Health is one of these. Their Training Workshops Unlimited has places for 500 PWID. This offers a fully structured training programme which aims to take participants through differing training stages to employment in the open labour market. The plan includes self care, basic work skills, production training, learnerships, a simulated job environment and finally full employment. Participants progress through the programme at their own pace and stop at the highest level that they can reach.

Oasis was originally founded in 1952 by a set of parents of children with ID who were not allowed access to schooling so the parents set up their own educational establishment. Today Oasis still run two day centres for 90 children with severe or profound ID, many of these children have more than one condition. Another four houses look after adults with disabilities. They also

provide two respite homes for carers. In addition they provide workshops and training. Their main employment schemes are a recycling centre, a bakery, a bookshop and two brick stores all of which generate income for the organisation and provide employment opportunities. The recycling unit employs 360 workers who would otherwise have no prospect of employment. Oasis recognises that many of the participants are unlikely to be able to participate in the open labour market so seeks to give people as meaningful employment as possible, with a choice of activities within their own workshops.

Education

The Department of Education acknowledged the need to include people with disability within the educational system in the 1995 White Paper on Education and Training.²¹ This was followed by two committees that investigated special needs and education. One of these was the 1996 National Commission on Special Needs in Education and Training and the other the National Committee on Education Support Services. This led in 2001 to the White Paper on Special Needs Education²² which developed an inclusive educational policy. Learners were to be integrated into the existing system whilst recognising that they had differing support needs.

The White Paper on Education and Training also noted that services for learners with special educational needs (LSEN) as well as other educational facilities were racially based and had to be changed to equal education for all.

In October 1996, the then Ministry of Education appointed the National Commission on Special Needs in Education and Training and the National Committee on Education Support Services to investigate and make recommendations on all aspects of 'special needs and support services' in education and training in South Africa. The final report was published by the Department of Education in February 1998 followed by a Consultative Paper (Department of Education. Consultative Paper No. 1 on Special Education: Building an Inclusive Education and Training System. August 30, 1999).

The final outcome of this was White Paper - number 6 Special Needs Education Building an Inclusive Education and Training System, published in July 2001²³. The policy states that special needs education is a sector where the ravages of apartheid remained most evident. Special schools were organised according to two segregating criteria, race and disability. The impact of this policy was that only 20% of learners with disabilities were accommodated in special schools. In 2001, statistics show that only about 64,200 learners with disabilities or impairments were accommodated in about 380 special schools throughout the country. Further it was estimated that there were 280,000 learners with disabilities or impairments who were not in the system at all. The report recommended moving towards inclusive education and training.

At this time the government ran special schools which catered for the needs of children classified with having moderate to mild intellectual disabilities (IQ levels of 30 - 70). Children with an IQ of under 35 are considered to be severely (IQ levels of 20 - 35) or profoundly (IQ levels of less than 20) intellectually disabled. These children were not admitted to special schools or to any other state schools and were cared for in NGO run special care centres which were funded by a subsidy paid by the Department of Health (not education) per person.

All schools were gradually to be adjusted to full service schools in order to be able to cater for all learning needs as the costs of changing all schools in the country at one time was both prohibitive as well as logistically impossible. The plan was for this to be achieved over 20 years. In order to facilitate this programme further, in 2005 the Department of Education developed the National Strategy on Screening, Identification, Assessment and Support which determined the nature and level of support required by learners with special education needs.

At higher education level the Department of Higher Education and Training has, since 2008, given full bursaries (rather than loans) to students with disabilities, to cover their education costs. This covers accommodation, books, transport, any necessary assistive devices and human support as needed. The scheme is administered by the National Student Finance Scheme (NSFAS), which annually publishes updated Guidelines for Students with Disabilities for the Department of Higher Education and Training Bursary Programme However only 1% of

students in higher education are disabled. Even though financial assistance may be available to the student many colleges and training establishments are not adapted sufficiently to enable students to be able to take up a place of study.

The National Plan (Vision 2030) is currently being implemented and as a part of it the Department of Basic Education has been working towards a policy of inclusive education which is to be in effect by 2020. The aim goes further than including people in education but looks to support those who are vulnerable because of some disability or because poor economic circumstance could make them prone to dropping out. Strong supporting mechanisms will be needed for this to be effective as South African teachers already face many challenges; poor training, large classes, pupils not being taught in a home language, poor social circumstances, cost of schooling, cultural views regarding education to name but a few.²⁴ Special schools face additional challenges to traditional schools. “The standard of curriculum delivery in these schools is poor, with a ‘one size fits all’ approach being used for children with intellectual disabilities.”²⁵ In addition only a limited number of subjects are offered at special schools which limits opportunities for further education and training.

In addition to the educational challenges children with ID are particularly vulnerable to sexual assault whilst at school. Disabled children’s vulnerability to sexual assault also appears high in institutions; studies show that 80-85 percent of criminal abuse of residents in institutions is never reported to authorities.¹²⁰ This is compounded by the lack of general information about, and understanding of, sexuality, particularly on the part of young people with intellectual disabilities²⁶

A lack of early childhood development and training is another shortcoming although in South Africa the introduction of grade R into the national curriculum is a major step forward. Such early educational practices are not usually found throughout Africa and in general children with disabilities start school much later than their peers and are sometimes kept in the same class for several years due to a lack of progress. Each of the nine provinces now has special schools for those with a variety of disabilities however those with profound intellectual abilities are still excluded although a recent court case will likely change this.

The governments 20 year review commented on pace of progress: “Access to special schools for children with disabilities has improved, with the number of public special schools increasing from 375 to 423 from 2002 to 2011. However, there is still a large percentage of children with disabilities not accessing formal education, either through special schools or mainstream education. In the workplace, employment equity and protection of workers from an unsafe work environment that could lead to illness and disability is ensured through effective legislation. Access to learnership programmes targeting youth with disabilities has promoted skills development and further raised awareness of disability. While major strides have been made to include people with disabilities in the mainstream, much still remains to be done to address persistent discriminatory attitudes, inaccessible public transport systems, barriers in the built environment that may prevent people with disabilities from accessing services, lack of access to communication and information as well as poor enforcement of key legislation impacting on disability. To address these challenges, the NDP includes plans to increase access to services, particularly quality education, and employment for people with disabilities.”²⁷

Funding and Education and Training

The Skills Development Act of 1998 sought to improve the employment prospects of persons previously disadvantaged by unfair discrimination, and to redress those disadvantages through training and education. In this regard, people with disabilities in particular, were targeted. To enable this in 2000 the South African government set up 21 sector training and education authorities (SETA's) as part of the national skills development strategy. These work with government, unions, employers, professional bodies and training institutions to set training targets and strategies for different sectors of employment and to train and better equip people for work through learnerships and other training courses. Part of the skills development levy is put towards projects that train and develop disabled people.

SETAS offer special grants to employers that employ learners from the designated groups (in terms of the Employment Equity Act 1998) on learnerships. Designated groups include black people (African, Asian, Coloured) and disabled people of any population group. The Department

of Labour, as the ministry responsible for overseeing SETA performance, require SETAS to expend discretionary and unclaimed grant monies in respect of the following targets: 4% disabled, 54% women and 85% black.

FASSET (the finance and accounting services SETA), for example, pays grants to employers, recognised tertiary institutions and professional bodies who take disabled persons onto learnerships and also provides a disability toolkit to help employers. The grant applies to people with disabilities in general and does not distinguish between intellectual and other disabilities. In addition to grants and subsidies an employer can claim a tax reduction from SARS of up to R50,000 per learner.

FASSET offered two types of payment in 2013; one a grant to employers who took learners onto learnerships (entry grant), and another for successful completion of a learnership (exit grant). These grants range from R8,750, (for a one year course, this includes both entry and successful completion of a learnership). This increases to R12,250 for entry and an exit grant of R22,25 for a two year course. This increases to R35,000 for both entry and exit grants for a three year course. Whilst this is lower than the amount paid several years ago it is still a substantial incentive to employers to take on and train a person with disabilities.

The FASSET Disability Toolkit,²⁸ developed in 2009 and revised in 2011, was put together after research showed that in many instances individuals are not confident in interacting with disabled people. Some reasons for not being comfortable with employing the disabled included: having no skills to manage them; thinking that the disabled cannot do what others can do; thinking that the disabled may injure themselves or others; thinking that it is costly to employ the disabled. FASSET were particularly keen to tackle disability issues as their own research showed that they were nowhere near reaching their targets; only 0.8% of people within that sector had a disability in 2011.

Despite these efforts the 2013/2014 Annual Report of the Commission for Employment Equity indicated that people with disabilities only accounted for 50,867 or 0.9% of the total workforce reported by all employers in 2013.

In 2012 SAFMH met with the Services SETAS to look at how services can be improved for PWID and mental health issues and to help them address skills and employment issues in this area.

Residential Facilities for PWID in the Western Cape

Across South Africa the Department of Social Development²⁹ subsidises 149 residential facilities run by NGO's, costing USD 4. 5 million. These 149 facilities provide residential care for a total 7,982 persons with disabilities (6,416 persons in urban and 1,566 in rural areas).

In 2006 Kleintjes³⁰ estimated that in the Western Cape 3.05% of the population had an ID, of these 2.5% had mild, 0.4% moderate and 0.15% profound ID, totaling 108,340 people. (More recent statistics by the Western Cape government estimated the population size as 180,500 in 2013).The vast majority of these live at home in a family setting. Some live in residential homes and others live in a few state institutions such as Alexandra Hospital in Maitland. (A combined total of 600 currently live in Alexandra and Lenteguer Hospitals). Alexandra Hospital has an acute unit for 18 residents which specialises in managing PWID and mental illness. Patients are moved to a step down facility once their condition has stabilised. Cases of readmission to the unit are high and there is an outreach services which works with families in the home in order to reduce the readmission rates.

For those in residential homes their disability grant is paid to the facility. In the Western Cape there are only 41 homes for people with ID. This province has the highest incidence of ID due to fetal alcohol syndrome. The majority of homes are provided by NGO's with some financial support from the government. The support needs for individuals within these facilities varies

enormously. Some of the residents have ID only, others have ID and physical disabilities such as mobility impairments, deafness, epilepsy etc. In addition many are aged and have additional health needs and complications as a result. The Provincial Government of the Western Cape pays a monthly sum of R2,064 (2013/14) per person towards care.

A study by McKenzie, McConkey and Adnams in 2012³¹ of 37 residential care facilities in the Western Cape found that 19 were in suburban areas, 10 in rural areas and 8 in townships. The homes had a median size of 49 with an overall total of 2,098 residents. Many of the residents had more than one disability. Multiple health conditions increases the needs of support workers to assist residents and thus increase the overall costs of running a facility. Despite this only the most basic of funding is available. In addition to support workers occupational and physiotherapists are often needed but no financing is provided to employ such specialist workers leaving organisations to fundraise for such facilities and service providers themselves. The majority of these homes are basic residential facilities, they provide little in the way of education and training. The majority of workers are also not trained in ID. Of the 37 facilities 22 included care provision for those with severe ID, 29 for moderate and 28 for mild ID. Twelve of the facilities excluded admission for those who were regarded as elderly or who had mental health problems. The majority of the residents had medication and mental health needs. Behavioral issues were evident for almost all the residents in 18 facilities. Despite this, until 2014, there was no home anywhere specialising in care for those with challenging behavior needs.

The residual impact of apartheid is very evident in some of the residential homes. For Includid which initially took all it's original residential intake from Alexandra and Lenteguer Hospitals over 50% of the residents are white and 38% are coloured. This is not because of any intake policy at the home itself but simply the outcome of history. Alexandra was an all white hospital and the majority of their patients were moved to Includid which sits in the grounds of the hospital. Likewise the original residents of Lenteguer were coloured. Historically there was no home for black PWID. Because of apartheid there has historically been a lack of indigenous practices and cultural awareness within residential homes which are generally run on the Western model.

A study of facilities within the Western Cape in 2012 found that all provided televisions, most had a garden, games room and transport. In terms of living facilities 50% of residents lived in single rooms, 23% in double room and that the rest lived in dormitories. Only 3 facilities provided facilities for married couples.³²

The prevalence of challenging behavior is significantly higher for PWID who have a diagnosed psychiatric illness such as anxiety disorders, mood disorders, schizophrenia etc and there will always be some people who require specialised services. It is estimated that at any one time between 40-50% of PWID will have such behavioural challenges and up to 80% of PWID will have some of these difficulties at some point in their life. In the Western Cape a new facility will shortly open to meet the needs of some PWID who have been rejected from other residential facilities as a result of their challenging behavior. This initiative will be jointly funded by the Provincial Departments of Health (R2 million) and of Social Development (R1 million). This comes after a private individual offered R12 million to support new group homes. This will be a pilot project to look at how public/private partnerships can effectively run such an organisation. "Support programmes for disabled people have been under-funded for a long time and I want to change that in the short to medium term in the Western Cape Government and to redirect more funds to disability related issues' said the Premier of the Western Cape, Helen Zille. Professor Craig Houseman of the Department of Health stated that "A developmental policy was developed to outline the approach of the Western Cape government to people living with intellectual disabilities and the actions taken to date are only part of what in time will become a more comprehensive departmental approach with NPO's working in the field."

Current proposals are to move away from looking at a person and their needs by virtue of their IQ alone but to look at the whole package of assistance that is required. This is in line with World Health Organisation guidelines recommending a person centred approach to disability. This would mean measuring a person's adaptive functioning and re-assessing on a regular basis. Such assessments would cover mobility, ability to engage in relationships, ability to communicate, ability to learn, any challenging behavior, ability to self care etc. Each person would have an individual care plan with expected outcomes. The needs assessment would then show what assistance was needed and this could then be costed and provided for. This would

encompass assessing the needs of the caring families as most PWID are cared for at home and not in an institutionalised or group homes environment. At regular intervals the plan would be updated depending on any progression made and according to any changes in life pattern that require adaption of the plan, such as ageing or a significant change in the approach to a particular disability.

The draft Western Cape government policy envisages working with NGO's to provide the necessary services. The proposed policy argues for the Department of Social Development (DSD) to be responsible the costs of NGO's utilities, services and staffing. Children with ID would be placed at an appropriate school. Protective workshops would move to the Department of Labour. All baseline needs would thus be paid for by DSD with the Department of Health providing individual health care needs, such as physiotherapy, occupational therapy, specialist nursing care, psychological counseling etc as necessary. Although this policy is a step forward it still does not seem to address issues such as increasing ageing of residents within facilities which will require greater funding to attend to all the resulting additional health needs. As the majority of PWID are looked after at home they face the prospect of having to move into homes for the elderly once their aged parents have died. This is a traumatic process for anyone but more so for PWID. Government spending plans do not a yet seem to cater for this large increase in numbers moving to such facilities in the next few years.

Funding of intellectual disability organisations.

There are very few funders of disability groups in South Africa, and almost none that focus on intellectual disability alone. The only consistent funders in this area are the Momentum fund through their corporate social investment programme and some private family trusts.

Since 2006 Momentum has contributed over R75 million to organisations in South Africa This support has been given to over 120 NGOs and educational institutions across the country who collectively provided key social welfare, health and education services to over 650,000 direct beneficiaries. It stands out as being the only CSI funder with a dedicated disability programme.

In the 2012/2013 financial year Momentum disbursed approximately R6.5 million nationally to partners within the disability sector. A few other organisations, notably ApexHi and the Anglo American Chairmans Fund also donate to disability groups as part of community development funding.

Several private trusts fund disability groups, one or two to intellectual disability groups specifically. The Vera Grover Will Trust is one of these. Professor Vera Grover was a former professor of psychology at the University of Cape Town and she left money for both further education and training for people working in the field of intellectual disability and for the funding of PWID who lack the financial resources to attend a facility of training, work or education.

The Rolf Stephan Nussbaum Foundation funds several initiatives in the mental health area. Set up in 2003 the fund covers applications for organisations involved with children, arts and culture, sports and animals, education and skills development as well as general development. Over the years they have made frequent donations to many organisations looking after intellectual disabilities.

For NGO's attempting to broaden their financial base their best hope is for funding from private trusts. But as trusts are, in their very nature private, there is no knowing how large the trust is, or what they fund, or when. Funding applications are therefore like throwing a dart in a dart board blind and useless for planning purposes. The amount of grant available is usually small, in the region of R10,000 to R20,000, not enough to undertake any capital project or to increase the staffing levels within facilities. Such donations are also nearly always for one year only and application has to be made again in subsequent years. Large multi-year funding is really needed for stability but is seldom available. Whilst the National Lotteries Fund has made significant grants available in recent years there is no guarantee of funding and the gaps between funding periods seems to get increasingly larger. At one point calls for proposals were annual but they have now become almost every two years and the grants awarded are smaller.

Government Disability Grants

The Integrated National Disability Strategy of 1997 was the first document that investigated the impact of paying disability grants, noting that to be disabled almost certainly meant exclusion from employment and thus from the opportunity to earn an income.” Poor people face a greater risk of impairment or disability. In addition, the birth of a disabled child, or the occurrence of disability in a family, often places heavy demands on family morale, thrusting it deeper into poverty. This means not only that there is a higher proportion of disabled people amongst the very poor, but also that there is an increase in families living at the poverty level *as a result of disability*. This phenomenon seriously hinders the development process.³³ The report noted the low development of literacy and basic skills that hindered access to employment opportunities. The disability grant paid at that time, apart from having a low take up rate, meant that recipients still lived in poverty as the payment was so low as to not even cover basic needs.

Currently all adults who are unable to work because of a mental or physical difficulty can receive a government grant after they have been medically assessed. Such a grant is paid monthly and is means tested. Under the age of 18 a parent or guardian applies for a care dependency payout instead. From 1 April 2013 for a person who is not married a grant is not paid if the person has assets worth more than R831,600 (the value of the persons home is not taken into account, so long as they live in it) and they have income of less than R49,920 per year. If a person is married no grant is paid if the joint assets are worth more than R1,663,200 (excluding their home) and joint income must be less than R99, 840 per year.

Currently the grant is worth R1,350 per year (April 2014) and can be paid until the age of 60 when it becomes converted to a state pension. Those who are unable to look after themselves can also receive a grant in aid of R310 a month (paid to the carer). In 2013/14 the number of people receiving the disability grant equalled 1,179,852, another 135,347 received the care dependency payout; and 71 879 received the grant-in-aid. This compares to 1,198,131 disability grants and 114,993 care dependency grants paid out in 2011/12.

The grants available are no-where near enough. If a person is brought up at home within the family then it is likely that at least one family member will have to live at home to look after them meaning another loss of income. If the PWID has a severe disability they will require 24 hour care, specialised therapy and schooling; such facilities barely exist in urban areas, in rural areas there are none.

Medical facilities are available at day hospitals for free but it costs money to get to and from these. In some places Dial a Ride is available but in many areas there are no such facilities. Specialised health facilities are limited and only available in urban areas, there is nothing in rural areas and multidisciplinary health services are few and far between. Co-morbidity is fairly common within ID, with epilepsy and cerebral palsy the most common co conditions.³⁴ Medicine and mobility aids are free for those in receipt of a disability grant. There are few opportunities for PWID to train for employment, their schooling is often limited and any jobs that are available are low paying yet few facilities are adapted to cope with dual conditions.

Persons with disabilities with a low income (and who satisfy other relevant criteria) are eligible for government housing subsidies. The subsidies are additionally funded to provide for specific needs in relation to the impairment and the particular environmental barrier experienced. There are also many persons with disabilities living in informal settlements and in shacks who are further disadvantaged by having no access to other basic amenities such as including sanitation and clean water. Municipalities have to keep a register of persons with disabilities living in informal settlements for the purpose of accelerating housing provision for this group.

Living in the community

In the late 1990's, throughout the world, governments started to move people with less serious disabilities away from institutional living and towards living in the community. This followed on from trials carried out in many countries where people who were moved to live in small community homes were shown to have developed far more than those who led sheltered lives in institutions, This policy covered those with lesser mental illnesses, intellectual and physical

disabilities who were thought able to live in small groups in the community along with a support network. For many countries this meant moving people into group residential facilities though some instead provided funding for people to rent their own home and then provided support workers to visit on an ad hoc basis. Often however these residential facilities generally focus only on looking after the residents basic needs rather than engaging the residents in any meaningful activity. Training which enables people – especially those with the most severe disabilities – to grow and develop as individuals is rare.

In South Africa the process of moving people out of institutions began in 1997. In the Western Cape the Associated Psychiatric Hospitals (APH) was formed from the regional hospitals. These comprised Valkenberg and Strickland Psychiatric Hospitals and Lentegeur (mixed psychiatric and ID) and Alexandra Hospitals (ID only). Over 2,000 employees worked in the hospitals and regional offices to serve the Western Cape. The first group home opened in 1997 in the grounds of Alexandra Hospital, Maitland. APH works with NGO's in providing group homes for previous residents of the hospital. When the scheme was first set up in 1997 there were questions as to the financial sustainability of the programmes as the government grant paid by social services to NGO's to deliver the services needed was regarded as inadequate. Patients (residents) were categorised into three degrees of care; those requiring assistance and care for 24 hours a day; those who required some help or supervision 8 hours a day and those who could live independently with once a week supervision.

One of these residential homes was Friends of Alexandra Hospital, later renamed as Includid. This is a partnership between APH, former Friends of Alexandra and the Western Cape Provincial Government Department of Health (DoH) and was set up to deal with the deinstitutionalisation of PWID from Alexandra and Lentegeur Hospitals in Cape Town. Many of the 70 residents lived in a hospital based environment for many years prior to moving into group homes in the grounds of Alexandra Hospital.

The environment was quite different to what they had experienced before. In the hospitals the residents lived in dormitory type wards of approximately ten people. They worked at various

jobs within the hospital during the day such as in the laundry room or in the workshops making baskets. Residents had no say as to what time they got up or what time they went to bed. They were fed a set menu at set times with no input from the residents themselves. If they failed to follow the rules they were punished and locked up in a room with no food. At weekends residents joined the nurses in a long walk with a picnic lunch as the main recreational activity.

Prior to the move the residents were given training in basic hygiene and other basic skills. The homes themselves were old support staff residences that were, even at that time, in need of substantial refurbishment. Even though the residents had previously been hospitalised the new arrangement fell under the Department of Social Development for funding rather than the Department of Health, with the housing itself falling under the Department of Public Works. No licence from the Department of Health was needed and therefore they DoH are not responsible for the premises.

At Includid the residents are encouraged to do as much as possible for themselves with assistance being offered by support workers only when needed. It is, in many ways, the opposite of the previous care model with the residents taking part in every decision that affects them. The project has 8 group homes in the hospital grounds and one outside in the local community that is occupied by those residents who are most able to live independently. There are three levels of living; minimal support living, partial support living and full support living. Minimal support living is for people who have self confidence in their abilities, can largely care for themselves and who are able to live alone or with other people. They can manage most day to day activities themselves but know how to summon assistance should they need it. Partial support living residents need assistance with tasks perhaps one to three times a week. Full support living residents require 20 hours hour care with one on one support.

At Includid in Maitland, Cape Town, residents help with tasks such as cleaning, shopping, deciding upon the menu, washing up and laundry and other day to day activities. They are expected to wash and dress themselves although a few need some assistance from a support worker. During the day many take part in basic work/skills groups which make paper, sew,

produce lavender bags, make beaded jewelry and work in the office. Others work in the gardens and help to produce some of the food requirements of the project. Residents also elect house representatives for each house and these meet once a week to discuss any issues in their houses. Basic literacy and skills training is also available and about half the residents attend these sessions regularly. Some residents also attend meetings as representatives of the Network on Disability and the Western Cape Forum on Intellectual Disability. Some of the residents have presented at Parliament in Cape Town and at disability groups in the UK.

Each resident has their own file which includes goals that they set themselves. They attend workgroups each day and one resident will be responsible for taking the register. Another will be responsible for making the tea and washing of cups afterwards. Shopping trips to the local supermarket are taken with the aid of a support worker. Every resident celebrates their birthday and chooses how they would like to spend their day; it might be a trip to a local restaurant or a trip to the waterfront or the movies. Residents make frequent use of the Dial a Ride service and sometimes take a train. At weekends many of the residents worship at one of the local churches.

Includid is however rather unusual in their approach. A study of residential facilities in the Western Cape³⁵ found that 'in nearly all facilities residents required help in managing money, personal care and use of the telephone; residents were not expected to contribute to household chores; residents were not expected to use public transport such as buses or taxis, nor to shop for groceries or clothes'....The residential facilities surveyed appeared to place little emphasis on developing their residents competence and improving their quality of life. For example, residents were not expected to undertake housekeeping chores, nor to integrate with the community. Although it might be assumed that they are incapable of doing so because of their impairment, this assumption does not correlate with the finding that most facilities cater for a range of severity of residents impairments from severe to mild. It would be expected that most residents would be provide opportunities to attain greater independence'.

Workgroups at Includid only cover very basic skills within the unit. Several work in the open labour market: one resident works at a local protective workshop, another helps at the local Friends Day Centre, one for Alexandra Hospital and two volunteers help out at the local library mending library books. The majority of residential facilities however do not offer any sort of training and development but merely residential care. Training to help people grow and develop is rare, the type of training offered is often less than is needed to make someone employable in the open labour market or to develop income generating skills.

The international model looks more at inclusion within society but within South Africa most of the residential homes seem to work in isolated pockets away from the very community in which they reside. This runs against international best practice. In addition PWID who work away from home may establish a better quality of life than those who remain within the residential facilities.³⁶

Whilst residential homes may cater for different levels of ID they often also need to be able to cope with a multiplicity of issues. In addition to ID many residents have some type of physical disability. Further funding is needed to adapt facilities to the mobility impaired, to install ramps, hearing aid loops, special visual equipment, adapted bathrooms etc all of which costs yet funding cannot readily be ascertained.

Conclusion

South Africa has good policies and is a signatory to all the major conventions yet implementation is ineffective in many areas. Resource constraints and a lack of a government champion to drive things forward has resulted in only partial or underfunded implementation on the ground. The stigma of disability has also rendered invisible many people who the policies are designed to help. Although South Africa has a Disability Rights Day and month there is still a general unawareness of disability issues. This lack of structured resources to help people along with a lack of awareness of issues has left many families struggling to cope. NGO's are

running underfunded care facilities and the lack of cohesive planning across government departments has left many issues and people behind.

Most studies undertaken in other countries into living in the community showed an increase in the development of individuals who moved into such facilities and away from institutions. "Yet in the twenty-five years through which the deinstitutionalisation process has taken place, the idea of developmental intervention to intellectual disability has almost completely disappeared as a priority. Long-term follow up of people moving from institutions in England showed that, after the initial rapid increase in independence on moving out of institutions, five and twelve years on there is no growth in adaptive behavior^{37 38}. One reason for the poorer performance of 'second-generation' community-based services may be that developmental intervention is no longer considered as important as it was.³⁹ This is certainly the case in South Africa where little development of residents takes place. In part this may also be due to the limited funding environment. Development of individuals is time heavy and expensive and most facilities can only afford general support workers rather than a variety of physical, psychological and occupational therapists and teachers which would develop a platform for future growth. Most residential places are simple places of safety. Moreover further investment is needed in both the infrastructure and support network. Many of the people who were initially moved out of institutions are now either in, or approaching, old age which brings a further set of health and support issues. In addition to the general problems of ageing further health complications arise from the long term use of medication and possible interaction with multiple drug use. In addition the number of people living in residential facilities is likely to increase as those who have hitherto been cared for by their families find that there is no-one left to care for them. No

planning seems to have been undertaken for these scenarios. Funding from government department currently only covers intellectual disability of ageing, it does not cover PWID who are aged, yet with they have increasing medical and social needs. More needs to be spent on PWID who have Down syndrome for example, for whom the signs of ageing start to appear from about the age of 40. They tend to suffer from sensory loss, osteoarthritis, and Alzheimers in particular.

Although there are facilities in urban areas for PWID many live in rural areas where there is little infrastructure and almost nothing in the shape of care and development facilities or even clinics and hospitals. This together with the African attitude of stigmatising those with disabilities condemns many thousands of people to living in lifelong isolation unless the government can start making inroads into both service provision and to changing awareness and perception of ID.

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