

# TWENTY YEAR REVIEW

## SOUTH AFRICA

1994 - 2014



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BACKGROUND PAPER:  
**DISABILITY**

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The background papers are written by officials in the Presidency and other government departments using inputs from literature reviews, commissioned research, government reviews and reports and roundtable discussions with a range of stakeholders. The views reflected in the background papers do not represent those of the Presidency, but rather reflect authors' views on sector developments.

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## **Acronyms and Abbreviations**

CASE	Community Agency for Social Enquiry
CBR	Community-based rehabilitation
CCMA	Commission for Conciliation, Mediation and Arbitration
CGE	Commission for Gender Equality
CI	Confidence interval
COIDA	Compensation for Occupational Injuries and Diseases Act
CSO	Civil-society organisation
Danida	Danish International Development Agency
DBE	Department of Basic Education
DBST	District-based Support Team
DHET	Department of Higher Education and Training
DOH	Department of Health
DPO	Disabled peoples' organisation
DPSA	Disabled People South Africa
DSD	Department of Social Development
DWCPD	Department of Women, Children and People with Disabilities
EWP6	White Paper 6 on Inclusive Education
GHS	General Household Survey
HEDSA	Higher Education Disability South Africa
HSRC	Human Sciences Research Council
ICT	Information and communication technology
ILO	International Labour Organisation
INDS	Integrated National Disability Strategy
MODE	Medunsa Organisation for Disabled Entrepreneurs
MPG	Mpumalanga Provincial Government
MSM	Men who have sex with men
NDP	National Development Plan
NEDLAC	National Economic Development and Labour Council
NGO	Non-governmental organisation
NIDS	National Income Dynamics Study
NSFAS	National Student Financial Aid Scheme
NSP	National Strategic Plan
NYDA	National Youth Development Agency
OHS	Occupational health and safety
OSDP	Office on the Status of Disabled Persons
PACSEN	Parents of Children with Special Education Needs
PALAMA	Public Administration Leadership and Management Academy
PANSALB	Pan South African Language Board
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PSC	Public Service Commission
RDP	Reconstruction and Development Programme
SADA	South African Disability Alliance
SAHRC	South African Human Rights Commission

SALGA	South African Local Government Association
SANAC	South African National AIDS Council
SASA	South African Schools Act
SASSA	South African Social Security Agency
SBST	School-based Support Team
SETA	Sector Education and Training Authority
SGB	School governing body
SOCPEN	Social Pension System
Stats SA	Statistics South Africa
TB	Tuberculosis
UIF	Unemployment Insurance Fund
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
WHO	World Health Organisation

## **Executive Summary**

This review sets out to understand the experience of persons with disabilities and the journey travelled over the past 18 to 20 years, as well as the extent to which the quality of life of persons with disabilities within South Africa has improved. While the focus on disability as a thematic area was welcomed across the disability sector, it does not detract from the fact that disability should ideally be located and analysed within other relevant thematic areas, either through disaggregated data or through the acknowledgement of persons with disabilities as a recognised minority group. While the reality of the lack of disaggregated data on disability leaves this approach of conceptualising, positioning and mainstreaming disability within each relevant thematic area a continued challenge, the use of available disaggregated data requires capacity for, and insight into mainstreaming disability in other thematic areas to contextualise the inequalities persons with disabilities experience.

## **The journey since 1994**

The new democratic government inherited a society that understood disability to be a personal tragedy that required a health and welfare response to “fix” the person and the situation. The ongoing difficulty and debate in measuring disability is reflected in the changing methodologies adopted over the past 20 years. At the centre of the debate lies the need for disabled people to be recognised as a distinct group of people with rights and responsibilities like any other citizen of a country, while they continue to experience high levels of exclusion and discrimination. Putting aside the debate on definitions, measures and categories, the essence of the narrative is captured in three phases of understanding the dynamics of the transition.

### *Laying the foundation of equality (before 1994–2000)*

The Disability Rights Charter of 1992 was of significant instrumental value in establishing the minimum demands of persons with disabilities in preparation for democracy in South Africa. This culminated in the inclusion of disability in the non-discrimination and equality clause (section 9) of the Constitution of South Africa (1996), and was followed by the *White Paper on an Integrated National Disability Strategy for South Africa*. The main vision of the Integrated National Disability Strategy (INDS) was “... a society for all, (where) the needs of all citizens constitute the basis for planning and policy, and the general systems and institutions of society are accessible to all” (Office on the Status of Disabled Persons, 1997).

### *Entrenching disability rights in government legislation (2001–2008)*

Within the context of the revision and redesign of the country’s policies, the development of several white papers served to inform legislation reform as South Africa moved into the new millennium. This phase also put focus on the development of strategies and programmes to guide the implementation of legislation that had already been promulgated. As the understanding of disability at the policy level moved beyond a health and welfare construct, this new approach had to be conceptualised in the process of addressing the residual effects of apartheid within

the health, social development, education, transport, communication and employment sectors, which are the core areas of service delivery for persons with disabilities.

*Strengthening the implementation of policies impacting on disability (2009–2013)*

South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol without reservation in 2007. This final phase in the twenty year journey since 1994 also observed important legislation and policies that is still needed to address disability issues.

**Reflection on achievements and reasons for celebration**

*Moving beyond disability as a health and welfare construct*

The journey reflected on throughout the three phases demonstrates that a shift in the understanding of disability had to take place for any real and significant progress to occur in the disability sector. The progress in the policy development stage and its significance, from the medical to the social- and rights-based approaches to disability, cannot be sufficiently emphasised. There is overwhelming consensus that the INDS presented the turning point for the disability sector in South Africa. Linked directly to the values and policy imperatives of the Reconstruction and Development Programme (RDP), it became the starting point of institutionalising change and setting the scene for the transformation of society and government. The journey described, as well as evidence in the literature on disability, demonstrates that the INDS represented the voice of people with disabilities to influence the development of progressive policies and legislation across the relevant sectors.

*Institutionalising the principle of self-representation of persons with disabilities*

Following the development of a rights-based legislative framework, another achievement to note is the institutionalisation of the principle of self-representation of persons with disabilities. Evidence of representation and participation after 1994 by persons with disabilities at national, provincial and local spheres of government, including in Parliament demonstrates the shift in attitude within the highest and critical offices of government and the state. At the level of community and society, organisations of disabled persons and for disabled persons were differentiated at grassroots level, with the former primarily mobilised for advocacy and change, and the latter to meet needs through service delivery. These gains in South Africa positively influenced development on the African continent, with 1999–2009 being declared the African Decade of Disabled Persons. This was a result of the efforts of the South African government and The Presidency in particular. The Decade of Disabled Persons was subsequently extended by the African Union to 2010–2019.

*Improving equity in access to services*

The Free Health Care Policy for pregnant women and children under the age of six years was extended to persons with disabilities in 2002 to facilitate access to health care, rehabilitation and assistive devices for indigent persons with disabilities.

Access to disability grants and care dependency grants grew steadily after the means test was revised and the criteria on assessments were relaxed when a panel of professionals other than doctors were able to assess the applications. There is evidence emerging in the first 20 year cycle of South Africa's democracy of depth and deepening efforts in taking the transformation agenda further.

*Local participation and developing partnerships to strengthen implementation of policies*

With the overall progress of transition from an apartheid government, transformation of the social agenda and tightening of legislation, attention shifted to the implementation of policies. This demonstrated the dual processes of government initiatives and civil society organisations intersecting to realise that partnerships are needed to effectively address the implementation of policies that impact on persons with disabilities. Where these partnerships were developed and strengthened through dialogue, joint planning and monitoring, and accompanied by the sharing of skills and expertise, visible impact could be seen.

**Overcoming challenges and doing things differently**

There is a need to build consensus on how the country can do things differently in championing the national disability rights agenda, against the background of the 2030 Vision for South Africa and the implementation of the National Development Plan.

*Adopting a unified definition of disability*

The struggle to define disability in a way that accurately and realistically encompasses the lived experience of persons with disabilities is a historical one, characteristic of power dynamics, prejudice and the social exclusion of those who do not "belong". A national dialogue is necessary to clarify the implications of the medical and social model of disabilities in order to effect and accelerate policy implementation and practice.

*Focus on equality of outcomes – rethinking the struggle for equity in access*

Government policies and programmes are designed to meet needs, and resources are allocated accordingly for the benefit of the greater public good. The large disparities between different race groups, geographical locations and between men and women that were inherited resulted in extremely uneven starting points when identifying needs, especially for persons with disabilities. In addition, disability does not only affect an individual, it affects an entire family (Taylor, 2002).

The allocation of resources based on the needs and demands of society is a complex situation for South Africa, as the democratic changes resulted in conflicting relations between communities and service providers, and especially between the disabled community and policy-makers with regard to wants/needs and demand/supply issues. Despite positive trends in participation rates and access to



services, the intended outcomes for the majority of persons with disabilities in South Africa have not been achieved within the set time frames and targets, especially regarding education and employment. Specific attention is required on institutionalising universal design and developing a better understanding of the cost of disability to the affected individual and family, as well as the state.

#### *Strengthening of the disability movement*

A vibrant and organised disability sector and in particular a strong representative voice of persons with disabilities, directly aligns with the call for an “active citizenry” referred to in the NDP in order to ensure policy influence. For the disability sector in particular, it is demonstrated that without the experience and expertise of disability issues by persons with disabilities themselves, policy-makers, service providers and the public at large will remain ignorant of their needs, or at best, sympathise with persons with disabilities and respond accordingly. The CRPD therefore requires of state parties to involve representative organisations of persons with disabilities in all matters affecting them, including the monitoring of implementation of the UNCRPD.

#### *Meeting differing needs – a developmental approach*

Persons with disabilities are not a homogenous group and have differing needs and experiences based on the type and severity of impairment, and the level and extent of attitudinal, physical and communication barriers. This is compounded by demographic characteristics of age, gender, location, sexual orientation, socio-economic status, and employment and marriage status. Some of the most vulnerable groups identified are youths with disabilities, women and children with disabilities, persons with disabilities living in rural areas, persons with intellectual and psycho-social disabilities and deaf persons due to the lack of access to sign language and interpreters.

#### *Towards a systems approach for effective disability intervention*

As the understanding of disability moved beyond a health issue, and as the voice of persons with disabilities became stronger, the complex nature of ensuring equality of outcomes for persons with disabilities unfolded over the twenty year period. A small achievement in one area had the potential to greatly impact on other dimensions of well-being. While access to services improved for the general population, in some instances it deepened inequalities between able-bodied and disabled citizens. An intervention in one sector is dependent on outcomes of another. This includes the timing and pace of delivery, priority choices and resource allocation, and the impact on each other to produce a web of interconnections and inter-relations. The understanding and development of several functional systems within a system of inclusive design, planning, implementation and monitoring is critical – with disability champions required at every level to ensure oversight and stewardship.

## **Recommendations**

### *Universal access and design*

Article 9 of the CRPD requires of governments to undertake appropriate measures to ensure that persons with disabilities are able to access, on an equal basis, the physical environment, public transport, information and communications, as well as other facilities and services open or provided to the public, both in urban and in rural areas. The most effective tool for achieving this is universal design, which benefits not only persons with disabilities, but also the broader diverse population.

### *Accountability and enforcement*

The polluter-pays principle should apply when public and private institutions flout constitutional entitlements and legislation that protect and promote the rights of persons with disabilities.

### *Partnership*

The right to live independently and to be included as an equal citizen in one's community requires partnerships between all sectors of society. Public sector institutions and service organizations need to align their services at community level to provide the seamless support services required to realize this right. Organs of civil society need to become active agents of change in fighting discriminatory attitudes and belief systems that push persons with disabilities and their families to the margins of society. Organizations of persons with disabilities, as the representative voice of persons with disabilities, need to strengthen their footprint at local level to empower persons with disabilities, to advocate for change, and to monitor and act upon rights infringements.

## Review

### 1. Introduction and background

By undertaking reviews after 10 and 15 years of democracy, The Presidency of South Africa set out to understand government's performance in meeting its objectives and improving the quality of life of all South Africans to inform future plans on areas of improvement.

The Twenty Year Review provides a special opportunity for South Africans to reflect on 20 years of freedom and democracy, and the progress we have made as a society. Using evidence to measure the achievements made provides the basis upon which to identify reasons to acknowledge and celebrate these achievements as a collective, while acknowledging that not all South Africans will have experienced this freedom and democracy in the same way, at the same pace and at the same depth, given the challenges that still remain. This is particularly the case for persons with disabilities in South Africa. The 20-year review provides a unique platform to put specific focus on the rights of persons with disabilities as one of the key thematic areas identified to include in the review process.

#### 1.1 Conceptual framework and purpose

This review sets out to understand the experience of persons with disabilities and the journey travelled over the past 18 to 20 years. Its aim is to determine the extent to which the quality of life of persons with disabilities in South Africa has improved. While the focus on disability through this dedicated thematic area was welcomed across the disability sector, it does not detract from the fact that disability should ideally be located and analysed in other relevant thematic areas of the review, either through disaggregated data or through acknowledgement of persons with disabilities as a recognised minority group in South Africa with the same rights as every other citizen. The reality of the lack of sufficient disability-disaggregated data leaves this approach of conceptualising, positioning and mainstreaming disability across the relevant sectors a continued challenge, although not impossible to overcome.

Therefore, the purpose of focusing on disability specifically is to consciously set the scene for the promotion of the rights of persons with disabilities as equal citizens within the National Development Plan (NDP), using evidence to assess the past as well as generate thought-provoking analysis and promote dialogue in order to positively influence change. The social model of disability<sup>1</sup> will be used throughout this review to analyse the legislative and programmatic outcome of government's initiatives, as well as to understand the progress made as a society. The social model of disability shifts the focus from the individual with a disability to the

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<sup>1</sup> During the early days of activism and transformation, the social model of disability presented a progressive way of understanding disability and challenged the medical understanding of impairment leading to individual tragedy

attitudinal, environmental and communication barriers that detract from equal participation and access.

Critical areas of work that need to be addressed will be highlighted, so that these become integrated into other relevant thematic areas in future interventions.

## **1.2 Methodology and sources of information**

A guiding principle in undertaking the Twenty Year Review was to build on existing knowledge to inform the various thematic areas that were included. Six streams of inputs were generated: commissioned research (Chappel & Rule, 2013); reflections by national and provincial government departments; a scientific literature search for disability which was undertaken by the Human Sciences Research Council (HSRC); a synthesis of existing research reports on disability informing the work of the Presidency since 1994 including the NDP; inputs generated at the stakeholder roundtable (disabled peoples' organisations (DPOs), researchers, academics and government officials) held on disability; and information contained in the baseline Country Report to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), approved by Cabinet in April 2013.

At the stakeholder roundtable, a reference group, comprising representatives from the core service delivery and coordinating departments – the Department of Basic Education (DBE), the Department of Social Development (DSD), the Department of Health (DOH) and the Department of Women, Children and People with Disabilities (DWCPD) – was nominated to synthesise and consolidate the findings. Due to the difficulty in attending the meeting held in Pretoria, inputs from organisations of and for persons with disabilities were requested through the DWCPD's Disability Rights Network to reflect on how the past 20 years of democracy impacted on the lives of persons with disabilities.

It is acknowledged that in the field of disability studies, many research gaps – including a scarcity of data, especially during the first decade of democracy – exist. This makes it impossible to adequately inform policy and practice. For the purposes of this review, there was a dependence on secondary data using desktop research methodology. Quantitative data, mainly from the various surveys conducted by Statistics South Africa (Stats SA), the development indicators and other scientific sources (as acknowledged), was used. As this review reflects specifically on the experience of democracy for persons with disabilities and measures changes in government and society, qualitative data generated through the submissions received in the consultation process of compiling the first UNCRPD Country Report was further supplemented by responses received from disability organisations through the Disability Rights Network.

This is an evidence-based narrative on 20 years of freedom and democracy in the disability sector. As such, case studies are used to illustrate and bring home key messages and lessons learnt to inform plans going forward, but difficult questions

are also posed to provoke deeper analysis and strengthen national dialogue on realising the rights of persons with disabilities.

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## 2. The journey since 1994

### 2.1. Understanding of disability and defining the scope

The new democratic government inherited a society that understood disability to be a personal tragedy that required a health and welfare response to “fix” the person and situation<sup>2</sup>. Before 1994, programmes designed to meet the needs of persons with disabilities by government were based on the similar value system about disability, building on the segregated apartheid policies and entrenching further violations of human rights and dignity. Children with disabilities, the majority being white, were found in segregated special schools, and the majority of adults with disabilities (72.6 percent) (Nkeli, 2008: 9) remained unemployed or at best were found in sheltered employment with no opportunities for career choices. The first democratic government thus inherited a legacy of discrimination, a lack of understanding of disability as a human rights issue and social exclusion of persons with disabilities.

Few official statistics were available on disability to inform the new democratic government on what constituted disability, where persons with disabilities across the race groups were located and what their socio-economic status was. The first attempts to measure the prevalence of disability since 1996, as shown in the distribution of disability among the major population groups in Table 1, demonstrates not only that disability differs across race groups, but that it is difficult to measure (there are huge differences in distribution between the three data sets). Furthermore, it brings to the fore the fact that disability is a social construct, perceived through the lived experience of the disabled person within a racially biased South African context, and measurement is highly dependent on the questions posed.

**Table 1: Distribution of disability among the major population**

	1996 Census	1998 CASE survey	1999 GHS
African	7.6	6.1	3.4
Coloured	3.7	4.5	4.5
Indian	4.2	4.8	2.2
White	3.5	5.3	3.2

Source: *Statistics South Africa, 1996; 1999*

The on-going difficulty and debate in measuring disability is reflected in the changing methodologies adopted over the past 18 years. At the centre of the debate lies the

<sup>2</sup> Mike Oliver refers to this as the individual model. The chapter entitled “Disabled People” in *Social Policy* (Alcock, Erksine & May, 2006) provides perspectives on the individual and social models of disability in social policy and related service delivery issues.

need to be recognized as a distinct group of people with rights and responsibilities like other citizens of a country. While policy-makers wanted to understand the extent and consequences of having a disability in order to formulate appropriate policies, allocate resources and develop programmatic responses, persons with disabilities embraced the window of opportunity presented by the new democratic dispensation to influence a change in attitudes and bring meaning to their lives. Chappel and Rule (2013) outline three phases that define the journey for persons with disabilities in South Africa since 1994. Putting aside the debate on definitions, measures and categories, the essence of the narrative is captured through these phases in understanding the dynamics of the transition, which demonstrate the progress made within the disability sector. Table 2 reflects the significant policy developments over these three phases.

## **2.2 Dynamics of the transition**

### **Phase 1: Laying the foundation of equality (pre-1994 to 2000)**

Persons with disabilities began mobilizing and organizing themselves from the mid-1980s in line with growing activism against apartheid, thereby aligning themselves with the broader liberation movement. Disabled People South Africa (DPSA) was formed in 1984 by a group of disabled activists to initiate change and create awareness of the rights of persons with disabilities. DPSA adopted a strategy of building local organizations to create a platform for persons with disabilities to empower themselves. This message spread across the poorest of communities, which started organizing themselves into self-help groups, aligned to DPSA, thereby initiating the formation of grassroots organizations to address disability and development. The Disability Rights Charter of 1992 was of significant instrumental value in establishing the minimum demands of persons with disabilities in preparation for democratic transition in South Africa.

The choices made to align DPSA to the political struggle, specific strategies adopted and actions undertaken by DPSA before 1994 laid the foundation of the principle of self-representation, advocacy and dignity (Chappel & Rule, 2013; Ka Toni & Kathard, 2011; Heap et al., 2009; Howell et al., 2006). With the recognition of the right to self-representation by the new democratic government, DPSA became the driving force of change for persons with disabilities across racial groups. The Office on the Status of Disabled Persons (OSDP) took position in The Presidency, the highest level of office in the country, to influence the transformation agenda. One of the main aims of the OSDP was to ensure the mainstreaming of disability across the public sector, as well as in civil society. Without this influence by DPSA, the RDP – as the visionary and strategic intent of the liberation movement – would not have effectively included the hopes and aspiration of persons with disabilities. The Disability Rights Charter, already documented in 1992, became the basis of minimum demands for persons with disabilities.

These efforts culminated in the inclusion of disability in section 9 of the Constitution, bringing recognition of persons with disabilities as equal citizens of the country. On the basis of the Constitution, the OSDP developed the White Paper on an Integrated National Disability Strategy for South Africa. The main vision of the Integrated National Disability Strategy (INDS) was “a society for all, (where) the needs of all citizens constitute the basis for planning and policy, and the general systems and institutions of society are accessible to all” (OSDP, 1997).

Informed by the United Nations Standard Rules for the Equalisation of Opportunities for Persons with Disabilities (United Nations, 1994) and the Disability Rights Charter, the INDS became the critical benchmark for all future disability legislation in South Africa, thereby further aligning national and international legislation and development. The public hearings held in the process of developing the INDS gave persons with disabilities across the geographical span of the country the opportunity to voice their needs and concerns. This, in essence demonstrated the beginnings of “inclusive and representative policy design” (Ka Toni & Kathard, 2011: 24) and also government’s commitment to self-representation for persons with disabilities.

The INDS represented a historical milestone in shifting away from the understanding of disability as a medical or health and welfare issue. The medical and social model of disability was officially documented to demonstrate this shift towards a rights-based approach, which is embedded within the social model and adopted in the INDS. With a focus on removing barriers faced by persons with disabilities in all facets of their lives, the INDS brought to the fore the roles and responsibilities of other key government departments, as well as civil-society organizations, in building a more inclusive society for persons with disabilities. The strategic timing of developing and documenting the INDS early in the country’s transformation agenda resulted in all relevant laws and policies that were revised or newly developed within the broader transformation agenda including disability as a rights-based issue. This is observed in the legislative context that unfolded with the Employment Equity Act (Act 55 of 1998), the Skills Development Act (Act 97 of 1998) and the Promotion of Equality and Prevention of Discrimination Act (PEPUDA) (Act 4 of 2000), constituting a non-discrimination transversal legal framework affirming the rights of persons with disabilities.

### **Phase 2: Entrenching disability rights in legislation (2001 to 2008)**

Within the context of the revision and redesign of policies in the country, the development of several white papers served to inform legislation reform as South Africa moved into the new millennium. This phase also put focus on the development of policy guides, strategies and programmes to ensure implementation. Even though the understanding of disability at policy level started moving beyond a health and welfare construct, the residual effects of apartheid still had to be addressed within the health, social development, education, transport, communication and employment sectors, which are the core areas of service delivery for persons with

disabilities. The racial discrepancies with regard to access to these core services are well documented (Nkeli, 2008), but embarking on a transformation agenda meant that these key government departments had to deal with redress by adopting the principle of improving equity in access across the sectors. The following milestones were seen to positively influence access to services for persons with disabilities.

**Table 2: Significant legislation, policies, conventions and guidelines pertaining to people with disabilities in South Africa**

1994–2000	2001–2006	2007–2012
<b>National legislation</b>		
Constitution of South Africa (1996)	White Paper 6 on Special Needs Education (2001)	The Sexual Offences Act (2007)
National Education Policy Act (1996)	Mental Health Care Act (2002)	Ratification of the UNCRPD (2007)
Integrated National Disability Strategy (1997)	Code of Good Practice for the Employment of Persons with Disabilities (2002)	Children’s Amendment Act (2007)
Housing Act (1997)		
Employment Equity Act (1998)	National Health Act (2004)	Social Assistance Amendment Act (2008)
Skills Development Act (1998)	South African Social Security Agency Act (2004)	National Skills Development Strategy (2010)
Skills Development Levies Act (1999)	Technical Assistance Guide to the Employment of People with Disabilities (2004)	
PEPUDA (2000)	Children’s Act (2005)	
National Rehabilitation Policy (2000)		
<b>International legislation</b>		
UN Standard Rules for Persons with Disabilities (1994)	UN Convention on the Rights of the Child (2001)	World Health Organisation (WHO) Community-based Rehabilitation Guidelines (2010)
UNESCO Salamanca Statement on Special Needs Education (2001)	UN Convention on the Rights of Persons with Disabilities – UNCRPD (2006)	

Source: Chappel & Rule, 2013

### Health

The responsiveness of the public health system was challenged due to higher demands and capacity constraints caused by the sharp increase in HIV/AIDS, tuberculosis (TB) and other communicable diseases. The Department of Health was expected to respond efficiently and effectively to these challenges, as well as to transform its administration. As outlined in the background paper on health, the transformation of the health sector was primarily aimed at addressing the inequities in access to health care by all South Africans. The primary health care approach and free health care policy for children under six years of age (as well as pregnant women) in particular, made health care more accessible to all, more so for children



with disabilities. Persons with disabilities receiving a care dependency or disability grant qualify for free health care.

Much more progress could have been made in ensuring equality with regard to access to health for persons with disabilities if the rollout of new health facilities and the upgrading of existing infrastructure, in particular in the vast rural areas, had followed the INDS guidelines with regard to barrier-free design.

In direct response to the INDS, the national Department of Health developed the National Rehabilitation Policy in 2000, which impacts directly on persons with disabilities regarding access to rehabilitation service delivery. Through this policy, government, in partnership with the disability sector, professional bodies and universities, as well as international partners, began to put the first principle of equalisation for persons with disabilities into practice. Access to rehabilitation services has been accepted widely as a “precondition for the equalisation of opportunities for people with disabilities” (United Nations, 1994).

Access to health care services is directly related to the early identification, prevention and management of impairments in order to minimise the effects of the impairment<sup>3</sup> leading to a disability. Table 3 shows that the categories of impairments that could lead to disability were affected by the measurement challenges referred to earlier. Communication, intellectual and emotional categories only started to emerge from 2007, with more awareness in identifying all types of disabilities through appropriate measures. Thus, a neglected area of need in disability was addressed through the Mental Health Care Act of 2002, which outlined the rights of persons with intellectual and psycho-social disabilities and also prioritised the provision of community-based mental health services.

**Table 3: Types of disability between 1996 and 2007**

Type of disability	1996	2001	2007
Sight	1 091 022	577 036	249 786
Hearing	383 408	313 585	180 397
Communication	-	--	91 065
Physical	557 774	557 512	769 772
Intellectual	-	-	128 841
Emotional	-	-	373 617
Mental	192 553	550 619	-
Multiple disabilities	154 236	257 170	122 741
<b>Total</b>	<b>2 378 994</b>	<b>2 255 982</b>	<b>1 916 219</b>
Percentage of population	5.9%	5.0%	4.0%

Sources: Census 1996, 2001, 2007

<sup>3</sup> “Impairment” and “disability” are terms used to promote an understanding of the medical and social models of disability, where “impairment” refers to structural changes in the body requiring medical intervention, while “disability” is related to social restrictions requiring changes within society (Oliver, 2003).

The success of health care promotion, prevention and management is demonstrated by how many lives are saved from premature death, and measured through the broad human development indicators of life expectancy, maternal mortality and child mortality.

The success of rehabilitation service delivery is demonstrated by how many persons with residual impairments (after lives have been saved) are integrated back into society with an improved quality of life to perform their roles and responsibilities as citizens. The National Rehabilitation Policy is thus an important milestone for access to rehabilitation service delivery in the health sector as the entry point.

The current reform of the health sector, through the introduction of the National Health Insurance, will go further to ensuring access and quality health and rehabilitative services in the health system, including both public and private, if adequately executed.

### *Social protection*

Section 27 of the Constitution makes provision for the development of an extensive social security system, and led to the South African Social Security Agency Act (Act 9 of 2004) and the establishment of the South African Social Security Agency (SASSA). Children and adults with disabilities across all race groups became entitled to social assistance through direct and unconditional cash transfers.

The background paper on Social Protection provides evidence that access to social grants has significantly reduced the levels of poverty in South Africa. This applies specifically to individuals and families affected by disability, as many scholars and institutions working in the field of disability conclude that disability is both a cause and consequence of poverty. Studies carried out on the South African population also found that access to disability grants played a significant role in household incomes and in changing the perception of those with disabilities (Loeb et al., 2008; Duncan et al., 2011). In addition to social grants, the Department of Social Development established a dedicated Disability Services Unit to work in partnership with non-governmental organizations (NGOs) to extend services to persons with disabilities.

### *Education*

The South African Schools Act (Act 84 of 1996) (SASA) gives expression to a transformed educational system. It provides for compulsory education for children between the ages of 7 and 15 years, promotes community involvement and formalizes parental involvement in schools through the establishment of school governing bodies (SGBs), outlining their specific functions in the provision of education, as well as the financial management of school funds. SASA does not differentiate between regular and special schools in the public sector, resulting in special schools being subject to the same management and governance

requirements to make special-needs education accessible and relevant to the communities it serves.

White Paper 6 on Inclusive Education (EWP6) marks a critical milestone in the educational sector by changing the focus from segregated facilities for children with disabilities to the provision of appropriate support in ordinary schools that will remove barriers to learning, including those that children with disabilities experience. At the time, basic and higher education was under one ministry. There was some emphasis on access to higher education through the different disability programs developed by universities and colleges, but the focus remained on the greatest need, which was access to basic education for children with disabilities.

### *Employment*

From the onset, skills development and employment opportunities have been identified in the transformation agenda as a fundamental human right for persons with disabilities. This took expression in the promulgation of the Employment Equity Act, which outlined measures to prevent discrimination in employment on the grounds of disability. In 2000, Cabinet set a target of 2 percent for employment equity of persons with disabilities for all government departments.

Transformation in the workplace was assured through the implementation of affirmative action measures for previously disadvantaged groups, based on race, gender and disability. In addition, the Skills Development Act outlined various forms of assistance to enable persons with disabilities to access learnership programmes. In recognition of building capacity among employers to deal effectively with disability issues, the Technical Assistance Guidelines on the Employment of People with Disabilities, documented by the Department of Labour in 2004, provided practical examples of ways in which to ensure reasonable accommodation and equality for persons with disabilities in the workplace. The Compensation for Occupational Injuries and Diseases Act (COIDA) was the earliest recognition of disability in the workplace due to occupational injuries, although the focus was on compensation rather than re-employment.

Persistent discriminatory attitudes and stereotypes about disability, inaccessible public transport systems, barriers in the built environment and a lack of access to communication and information, as well as poor enforcement of the Employment Equity Act, have detracted from progress being made in the employment of persons with disabilities in both the private and public sector.

### **Phase 3: International alignment and focus on strengthening the implementation of policies that impact on disability (2009–2013)**

South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol without reservation in 2007, thereby committing the South African government to respect and implement the rights of

persons with disabilities, as documented in the various articles. The baseline country report was to be submitted in May 2010, two years after the convention came into power, but the institutional restructuring of the OSDP into a Ministry of Women, Children and People with Disabilities (DWCPD), as well as weak information management systems in many government departments, delayed the process of coordinating the compilation of the report. Given the urgency within a newly formed ministry, the DWCPD finalised the report in 2012, and it was approved by Cabinet in April 2013 as the most comprehensive assessment of the rights of persons with disabilities to date. Key areas of development in South Africa relating to disability as indicated in the report are referenced in this review process, especially to demonstrate the changes observed since 1994 and to draw on the lessons learnt.

This final phase in the journey since 1994 also observed the development of important legislation and policies needed to address disability within certain sectors. The Criminal Law (Sexual Offences and Related Matters) Amendment Act (Act 32 of 2007) protects persons with intellectual and psycho-social disabilities from, among other things, sexual exploitation and sexual grooming, and protects persons with mental disabilities from being used for pornographic purposes. The act further provides, among others, for the establishment of a National Register for Sex Offenders, in which the particulars of sex offenders convicted of any sexual offence against a child or a person who is mentally disabled are recorded.

The South African Local Government Association (SALGA) developed the Disability Framework for Local Government (2009–2014) as a response to the ratification of the UNCRPD, and it strategically addressed disability in the local government sphere for the first time in the country. This framework guides municipalities to develop partnerships with the disability sector that promote equal opportunities and access to services at the local level for persons with disabilities. However, governance and administrative challenges in the local government sphere detracted from the effective implementation of the framework at municipal level. The National Land Transport Act (Act 5 of 2009) recently included accessible transport for persons with disabilities in its amendment, as transport challenges remain a neglected area of development.

### **3. Reflection on the journey**

#### **3.1. Moving beyond disability as a health and welfare construct**

The journey reflected on throughout the three phases in the first section demonstrates that a shift in the understanding of disability had to take place for any real and significant progress to occur in the disability sector. As long as social exclusion exists at any level of society, development is impossible. The thrust for change occurred in the first phase of the journey, when the vibrancy, energy and collective leadership of DPSA challenged and influenced the status quo and inherited understanding of disability in the country. This included transformation in the disability civil-society sector itself, with persons with disabilities taking control of a

number of disability service organisations such as the Deaf Federation of South Africa (formerly the South African National Council for the Deaf), the establishment of Deafblind South Africa, and so on.

Progress in the policy development stage and the significance of this, from the medical to the social and rights-based approaches to disability, cannot be sufficiently emphasised. Without this shift, persons with disabilities would have missed the opportunity to position their struggle within the broader socio-political context of the segregated South African society of 1994. This set the scene to locate disability rights in all sectors of government and society, with government becoming the first point of activism. The timing and actions of DPSA proved that the best time to influence change is during a transition. The desired and intended consequences of awareness-raising were achieved and the process of achieving broader outcomes was initiated.

However, shifts in attitudes and actual changes in behaviour require that the very foundations upon which discriminatory beliefs and practices are built should be systematically dismantled and rebuilt, using the desired progressive rights-based framework. Lessons learnt from the broader struggle for equality in South Africa reveal that this is no easy task. A challenge lies behind every achievement made. The achievement of moving beyond disability as a health and welfare construct in the policy and legislative dimension has the challenge of keeping the momentum going by influencing policy implementation and practice. Advocates in the disability sector report that the “language of impairments/medical model” still dominate the various laws, policies, strategies, programmes and practice in local contexts where implementation occurs. This perpetuates the understanding that persons with disabilities experience a personal tragedy due to an impaired body, requiring an intervention to “fix” that impairment.

Saving lives, reducing the burden to disease and injury and preventing impairment through medical interventions is the basis of any public health response. The primary prevention of impairments and premature death is a humanly desirable health outcome, measured by the demands and need for health care worldwide. However, promoting life and preventing disease, injury and death is also the function of health promotion by other sectors, such as environmental health, local government and access to basic services (water, electricity, sanitation), as well as transport and infrastructure, in reducing the number of road accidents as a cause of impairments. Secondary prevention in reducing the impact of residual impairment delves into the social causes of disability. Thus, the concepts of the medical and social models need to be understood within the context of transformation.

The extent to which all barriers that prevent equal participation by persons with disabilities in daily life are removed becomes a composite measure in understanding the prevalence of disability. The difficulty in measuring prevalence rates was noted

earlier, with its resultant lack of understanding and attitude towards disability posing as the greatest challenge. While subjective reporting on impairment, such as the survey data quoted, is available for planning, there is clearly a gap in understanding the extent to which other barriers, which perpetuate the “state of disability”, prevent optimum participation. What is evident is that the South African society, has not yet sufficiently engaged with the dynamics and implications of the two models or approaches to disability.

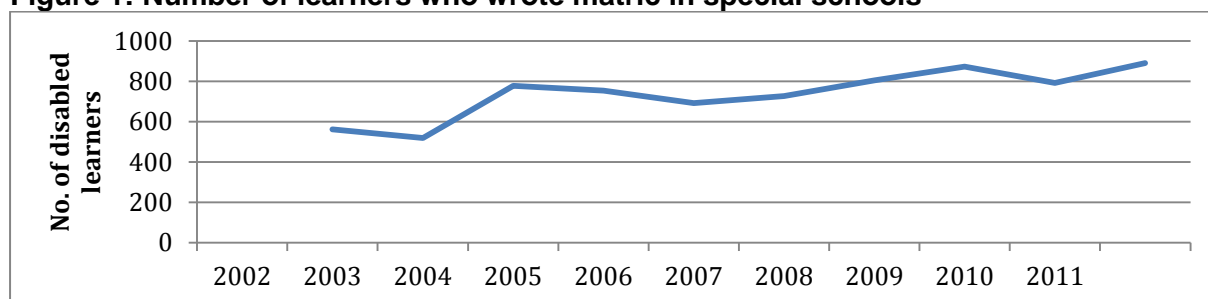
### 3.2 Improving equity in access

In the inheritance of such a segregated society as South Africa in 1994, achieving equity in access to all aspects of public participation and service delivery was the most important goal of government. Persons with disabilities were already at a greater disadvantage than those in the mainstream of an inequitable society, making the goal of equity in access a critical deliverable to be met for disability. This intention was seen across sectors as the legislative and policy context itself was transformed into a progressive rights-based framework.

The free health care policy for pregnant women and children under the age of six years was extended to persons with disabilities in 2002 to facilitate access to health care, rehabilitation and assistive devices by eliminating the barrier of health care costs associated with disability.

National Treasury made additional funds available in 2006–2011 following an audit of all special schools in 2002, which found that 60 percent of districts in the country had no special schools (DWCPD, 2012). This was aimed at the improvement of the most neglected special schools, the training of teachers and the provision of assistive devices and specialized equipment. More schools were built as part of this programme in light of inequitable distribution of special schools in the country. Figure 1 shows the steady albeit slow increase in the number of learners who wrote matric in special schools.

**Figure 1: Number of learners who wrote matric in special schools**



Source: *Development indicators, 2012*

Access to disability grants and care dependency grants has grown steadily (Table 4) with the revised means test and relaxed criteria on assessments where a panel of team members other than doctors are now able to approve grants. South Africa’s

approach to poverty alleviation is regarded as a model of innovation, due to the unconditional nature of social grants, the linking of benefits with the range of basic services, and its method of delivery through the coordination of efforts by departments and intersectoral arrangements.

**Table 4: Number of persons accessing disability grants and care dependency grants (1996–2012)**

Grant type	1996/97	1998/99	2000/01	2002/03	2004/05	2006/07	2008/09	2010/11	2013
Old-age Grant	1 637 934	1 812 695	1 900 406	1 943 348	2 124 984	2 195 018	2 390 543	2 678 554	2 873 197
War Veterans Grant	13 473	9 197	5 617	4 638	2 963	2 340	1 500	958	587
Disability Grant	711 629	633 778	655 822	840 424	1 293 280	1 422 808	1 286 883	1 200 898	1 164 192
Foster Care Grant	42 999	46 496	66 967	83 574	195 454	400 503	474 759	512 874	372 960
Care Dependency Grant	2 707	16 835	33 574	42 355	86 917	98 631	107 065	112 185	117 884
Child Support Grant		21 997	1 111 612	1 998 936	4 165 545	7 863 841	8 765 354	10 371 950	11 341 988
<b>Total</b>	<b>2 408 742</b>	<b>2 540 998</b>	<b>3 773 998</b>	<b>4 913 275</b>	<b>7 869 143</b>	<b>11 983 141</b>	<b>13 026 104</b>	<b>14 877 419</b>	<b>15 944 527</b>
<b>Growth rate</b>		5.49%	48.52%	30.19%	60.16%	52.28%	8.70%	14.21%	7.17%

Source: Department of Social Development, SOCPEN (Social Pension System), end of March 2013 take-up rates <sup>4</sup>

Access to justice through the Constitutional Court is demonstrated in the four cases in Table 5, where all the rulings were in favour of the complainants for discrimination experienced on the basis of a disability. With only four cases appearing at the courts for disability, it is apparent that citizens and society at large have not yet accessed the courts enough to promote their rights. With more awareness of both their rights and information on how to exercise those rights, persons with disabilities will make greater demands on services and contribute towards a functioning democracy.

With increasing attention being placed on achieving equity in access to goods and services across the public domain, it also became evident that other key, but silent policy directions were not emphasized and implemented effectively. For persons with disabilities, access to information by relating to their rights and entitlements has been implemented at a slower rate than for their able-bodied counterparts due to inaccessible communication channels to filter information. In addition, policy guidelines on providing “reasonable accommodation” and for universal design across all sectors were not understood well and therefore not implemented consciously through programmatic interventions. Without universal design and reasonable accommodation (and assistive devices) in the home, school, work and community environment, policy imperatives – no matter how progressive – remain an empty shell of promises for persons with disabilities. Desired outcomes for the realization of

<sup>4</sup> This table was taken from the chapter on Social Protection to reflect the increase in access to both the Disability Grant and the Care Dependency Grant.

the rights of persons with disabilities are impossible without appropriate environmental universal design and/or redesign.

**Table 5: Access to justice as demonstrated by four cases**

Case details	Year	Complaint	Outcome
1. Prinsloo vs Van der Linder	1997	Unfair discrimination on the basis of disability	The court ruled in favour of the complainant and endorsed that “at the heart of the prohibition of unfair discrimination lies recognition that the purpose of our new constitutional and democratic order is the establishment of a society in which all human beings will be accorded equal dignity”.
2. WH Bosch vs Minister of Safety and Security and Minister of Public Works	2005	Inaccessibility of courts	The Equality Court in Port Elizabeth found the discrimination to have been unfair.
3. Lettie Hazel Oortman vs St Thomas Aquinas Private School	2010	Discrimination against a child with a disability to access education	The school was obliged to readmit Chelsea Oortman and to take reasonable steps to remove all obstacles to enable the children to have access to all the classrooms and the toilet allocated to her by using a wheelchair.
4. Standard Bank Limited vs Commission for Conciliation, Mediation and Arbitration (CCMA)	2008	Bank employee was dismissed after being injured in a car accident	The court ruled against the bank for not complying with the Code of Good Practice on Dismissal, as the bank failed to accommodate the employee, which rendered dismissal automatically unfair.

### 3.3 White Paper on the Integrated National Disability Strategy

There is overwhelming consensus that the INDS presented the turning point for the disability sector in South Africa. Linked directly to the values and policy imperatives of the RDP, it became the starting point of institutionalizing change and setting the scene for the transformation of society and government. The journey described, as well as evidence in the literature on disability, demonstrates that the development of the INDS, influenced by the Constitution and PEPUDA, represented the voice of persons with disabilities to influence the development of progressive policies and legislation across the relevant sectors.

### 3.4 Institutionalising the principle of self-representation of persons with disabilities

Following the development of a rights-based legislative framework, another achievement noted in the disability sector is the institutionalisation of the principle of self-representation of persons with disabilities. The introduction into disability discourse and subsequently into public policy by DPSA of concepts like “empowerment”, “participation”, “representation”, “equal opportunities” and “social inclusion” were foreign to the traditional service sectors and to the professionals who had worked in the field of disability in the past. These concepts are the foundation of a democratic state and the basis of the social model of disability referred to earlier.



Persons with disabilities aspired to self-representation at all levels, but the challenge came in institutionalising this principle to influence policy development and implementation. Evidence of post-1994 representation and participation at national, provincial and local spheres of government, including in Parliament by persons with disabilities as champions, demonstrates the shifts in attitudes in the highest and critical offices of government and the state.

In addition, persons with disabilities represent the interests of the disability sector in a number of other public institutions, such as the South African Human Rights Commission (SAHRC), the Commission for Gender Equality (CGE), the National Youth Development Agency (NYDA), the Public Service Commission (PSC), the National Economic Development and Labour Council (NEDLAC), the National Lotteries Board and its distributing agencies, the Unemployment Insurance Fund (UIF), the Commission on Employment Equity, the National Development Agency, the Pan South African Language Board (PANSALB), the National Skills Authority and the South African National Aids Council (SANAC).

At the level of community and society, organisations of disabled persons and for disabled persons were differentiated at grassroots level, with the former primarily mobilised for advocacy and change, and the latter to meet needs through service delivery.

These gains in South Africa positively influenced development on the African continent, and 1999–2009 was declared the African Decade of Disabled Persons. While tools to monitor and measure the extent of influence that will serve to strengthen active participation in civil society and internationally, and the social compacts needed to advance the implementation of policies, there is no disagreement that this presents reason to celebrate our democracy.

### **3.5 Decent work and economic empowerment**

Evidence of deepening efforts in taking the transformation agenda further is emerging from the first 20-year cycle of South Africa's democracy. Government, as an employer, is also subject to meeting the employment equity targets. In 2005, Cabinet set a target of 2 percent for employment equity of persons with disabilities for all government departments. Although steady progress has been made over the past eight years, from 0.16 percent in 2005 to 0.32 percent in 2010/11 and 0.36 percent in 2011/12, it still falls far short of the 2 percent target. Several frameworks and initiatives to address compliance with regard to the representation of persons with disabilities have been developed, including the following:

- JobACCESS Strategic Framework for Recruitment, Employment and Retention of Persons with Disabilities in the Public Service Workplace (2009)

- The development of an accredited training course in disability management in 2011 by the Public Administration Leadership and Management Academy (PALAMA)

A total of 5 133 out of 9 541 (54 percent) enrolled learners with disabilities who were registered in learning programmes across 15 sector education and training authorities (SETAs) successfully completed their learnerships during 2008–2011, and 45 percent obtained employment after completing their learnerships. These outcomes would not have been possible without the active role of business, such as Pick n Pay, in extending employment opportunities for persons with disabilities. In addition, the Services SETA introduced a reasonable accommodation subsidy for learners with disabilities who needed support to participate in learnerships in 2012.

An encouraging development in empowering persons with disabilities on the economic front was the launch of the Medunsa Organisation for Disabled Entrepreneurs (MODE), which had enabled 532 persons with disabilities to establish their own income-generating micro-enterprises over the years, while creating 900 jobs.

Structural and institutional changes with the implementation of disability focal points and the establishment of the Ministry for Women, Children and People with Disabilities have also served to increase the awareness of disability rights, and to strengthen coordinated and strategic endeavours to integrate and mainstream disability across the relevant sectors. Isolated good practice in government highlights the commitment towards and the use of an enabling legislative environment to implement policies, address needs and deepen transformation.

#### **Kha Ri Gude mass adult literacy campaign**

A specific reason for celebration is the exceptional achievement for adults with disabilities by the Kha Ri Gude mass adult literacy campaign. As also highlighted in the chapter on Rural Transformation, this initiative by the Department of Basic Education reached 129 121 adults with disabilities between 2008 and 2011. Among these, 33 percent had visual impairments, 22 percent had physical impairments and 14 percent had hearing impairments. To address their learning needs, the teaching material was adapted for use in Braille and in eleven languages for use by those with hearing impairments. A combination of effective teaching methods, adaptive materials and committed and capacitated staff produced the desired results of achieving the literacy outcomes.

### **3.6 Local participation and partnerships to strengthen the implementation of policies**

With the overall progress of the transition from an apartheid government, the transformation of the social agenda and the tightening of legislation, attention shifted to the implementation of policies. This demonstrated the dual processes of government initiatives and civil-society organisations (CSOs) intersecting to realise

that partnerships are needed to effectively address implementation of policies impacting on persons with disabilities. Where these partnerships were developed and strengthened through dialogue, joint planning and monitoring, with the sharing of skills and expertise, the effects were tremendous.

### **Inclusive education**

One of the earliest initiatives of partnership-building was seen in the development of White Paper 6 on an Inclusive Education System. In 2002, the Department of Education, in collaboration with NGOs and higher education institutions in three provinces (North West, the Eastern Cape and KwaZulu-Natal) carried out a pilot project on the implementation of inclusive education in South Africa, funded by the Danish International Development Agency (Danida). As a result of this pilot project and with the assistance of the disability NGOs and higher education institutions, the Department of Education developed various documents and guidelines on the screening, identification and assessment of learners for appropriate placement. Children with disabilities who are also incontinent continue to experience major challenges in the classroom. The roll-out of incontinence clinics at special schools, initiated by the organisation Parents of Children with Special Education Needs (PACSEN), has begun to address this barrier. The challenge of overcoming barriers to learning (such as pregnancy, HIV and poverty) in mainstream education – those relating to learners with special needs specifically – can only be understood and emphasised by those affected directly.

### **Disability in higher education**

The organisation Higher Education Disability South Africa (HEDSA) represents disability units at universities and contributed significantly to policy development and implementation. Support services are available through disability rights units at 11 higher education institutions for students with disabilities, albeit at various levels of development. In 2008, the former Department of Education introduced a bursary scheme for students with disabilities studying at one of the 23 public higher education institutions to provide financial support for students with disabilities who are academically able but in need of financial aid. The bursary covers tuition, books and other study material, accommodation and important, transport, as well as assistive devices or human support that may be required. The scheme is administered by the National Student Financial Aid Scheme (NSFAS), which annually publishes updated guidelines for students with disabilities for the Department of Higher Education and Training (DHET) Bursary Programme.

### **Rehabilitation**

A well-documented strategy on community-based rehabilitation (CBR) was accepted by the disability movement as the strategy that embraced social inclusion and representation by persons with disabilities. This strategy was initiated by NGOs before 1994 and was officially piloted in three provinces (Mpumalanga, the Eastern Cape and the Western Cape) after 1994. The Mpumalanga Provincial Government

(MPG) entered into a formal partnership with DPSA through a contractual agreement for developing a programmatic response to address extensive service delivery needs for persons with disabilities in this province. The MPG provided public-sector financial support for CBR services managed and implemented by persons with disabilities themselves, bringing peer and family counselling and referral services to communities. The challenge now is to extend this empowerment model across all municipalities in all nine provinces.

### Disability and HIV

The disability sector has undertaken several initiatives since 1999, including a Disability and HIV Summit and the submission of a consolidated document on disability and HIV to the Department of Health in 2000 to highlight the need to address disability in the national strategy. The National Strategic Plan of 2000 to 2005 did not identify persons with disabilities as a vulnerable group (Chappel & Akolo, 2008). As reported in the first country report, the partnership between disability organisations through the South African Disability Alliance (SADA), SANAC, the OSDP and the Joint United Nations Programme on HIV/AIDS (UNAIDS), a joint programme on HIV/AIDS culminated in a report on HIV, AIDS and disability in South Africa, published by SANAC in 2008.

Findings from a survey conducted in 2009 provide the scientific evidence of HIV prevalence among persons with disabilities as a high-risk population (see Table 5). In the most recent National Strategic Plan (NSP) (2012–2016), persons with disabilities are recognised specifically as a vulnerable group and their particular needs are taken into account in the objectives and interventions detailed in the document. For example, Intervention 3.1.2 in the NSP 2012–2016 insists that HIV screening and testing facilities must be physically accessible, and that accessible communication must be used to facilitate the inclusion of persons with disabilities.

**Table 5: HIV prevalence among the populations most at risk in South Africa**

Population at risk	N	Percentage HIV+	95% CI
African females, 20–34 years	1 395	32.7	29.7–36.0
African males, 25–49 years	944	23.7	20.1–27.7
Males, 50+ years	946	6.0	4.4–8.1
Men who have sex with men (MSM)	86	9.9	4.6–20.2
Recreational drug users	490	10.8	7.2–15.8
High-risk drinkers	965	13.9	10.4–18.2
People with disabilities	458	14.1	9.9–19.6

Source: Shisana et al., 2009

## 4. Overcoming challenges and doing things differently

A reflection on the journey travelled by persons with disabilities and their representative organisations since 1994, and identifying the achievements and reasons to celebrate South Africa’s young democracy, will not be complete without acknowledging the challenges that remain, despite the best of intentions. Drawing lessons from the past and building on positive experiences require all actors in this

process to delineate the drivers of change and understand why there are achievements in some areas and not others. There is a need to build consensus on how the country can do things differently as government embraces the 2030 vision for South Africa and begins to implement the NDP.

#### **4.1 Adopting a unified definition of disability**

The struggle to define disability in a way that accurately and realistically depicts the lived experience of persons with disabilities is a historical one, characteristic of power dynamics, prejudice and the social exclusion of those who do not “belong”. This struggle is best described by Soudien and Baxen (2006):

“... each definition is embedded within the broader constructs of how society works, who is in and who is out, and under what conditions decisions are made. How definitions work to frame, organise and create policies and the social practices that flow from them, is nowhere clearer than in the field of education. It is crucial, therefore, that these definitions be understood as emergent from particular histories and discursive formations.”

At the heart of the struggle lies the search for an identity and a sense of belonging by persons with disabilities. If the early understanding of disability, which was based on a limiting medical definition and equated with a deficiency, influenced measures that resulted in policies and practices that excluded persons with disabilities in mainstream society for decades, then the instrumental use of a definition based on human rights and a developmental model has the potential to catalyse change. The prevalence of intellectual disabilities was documented only after the definition of disability was better understood and led to the inclusion of intellectual impairments as a variable. Even if disability has been understood differently, measured differently and therefore provided for in different ways since 1994, it becomes evident that its “evolving” nature mirrors the context and society within which persons with disabilities live.

Currently, the definition of disability varies across legislation and contexts, with too many national departments still documenting and implementing policies using impairment as the sole axis for defining disability. The presence of impairment is a critical component of defining disability, but the challenge has been in defining the contexts in which barriers limit participation and access, and detract from equity and equality.

A national dialogue will be needed to clarify the implications of the medical and social model of disabilities in order to effect and accelerate policy implementation

and practice. The DWCPD<sup>5</sup> had committed to finalising a national definition of disability by undertaking an “extensive participatory process over the next 12 months to accelerate the review of the INDS and to domesticate the convention through the development of transversal national policy and legislation” (DWCPD, 2012).

#### **4.2 Focus on equality of outcomes – rethinking the struggle for equity in access**

Government policies and programmes are designed to meet needs, and resources are allocated accordingly for the benefit of the greater public good. The large disparities inherited between different race groups, geographical locations, and between men and women, resulted in extremely uneven starting points when identifying needs, especially for persons with disabilities. In addition, disability does not only affect an individual; it affects an entire family (Taylor, 2002). The allocation of resources based on need and demands by society is a complex situation for South Africa, as the democratic changes resulted in conflicting relations between communities and service providers, and especially between the disabled community and policy-makers. Despite positive trends in participation rates and access to services, the intended outcomes for the majority of persons with disabilities in South Africa have not been achieved within the time frames and targets set, particularly with regard to education and employment.

#### **4.3 Prioritising the case of children and youth with special needs**

The provision of education for children and young persons with disabilities requires urgent attention, starting with access to inclusive early childhood development opportunities. The progressive and transformative policy imperatives embarked upon through the development of White Paper 6 on Building an Inclusive Education System have not been felt by the majority of persons with disabilities. This is attributed to implementation being “... too gradual and the time frame too extended to make a significant impact...” (DWCPD, 2012). Further and more disconcerting is that the “... incremental implementation of White Paper 6 over 20 years is not consistent with section 29 of the Constitution of the Republic of South Africa.” The Oortman case in the Equality Court in 2010 set an important legal precedent, although it was the only case during the latter part of the review period that challenged a school for not providing reasonable accommodation needs for a learner with a disability. As more parents and children with disabilities realise their right to education, more cases may emerge thereby challenging service delivery.

Successful implementation of Education White Paper 6 required the transformation of mainstream schools as well as special schools. Capacity constraints within mainstream or ordinary schools resulted in the objectives of inclusive education not being sustained in the pilot schools. Special schools were required to ensure that all

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<sup>5</sup> At the time of writing this report, the DWCPD had documented this intention, although post the 2014 elections, the restructuring of this Department will require disability champions to continue with critical work identified going forward.

policies were developed in line with national policies, including admissions, language, curriculum and so on. A comprehensive audit of all special schools conducted in 2002 highlighted significant challenges, as well as unsafe and hazardous conditions at the majority of special schools under question. This required the strengthening of monitoring and oversight mechanisms to hold non-performing school and district officials accountable, but these systems were largely dysfunctional.

To date, compulsory school attendance for children with disabilities has not effectively been monitored and enforced. Table 6 provides a snapshot of the General Household Survey (GHS) data of the extent to which children with disabilities are not receiving any education. Of the 703 159 children identified with a disability, only 33.6 percent are registered with either special schools (47.3 percent) or mainstream schools (52.7 percent). More than 60 percent of children with disabilities are not registered to receive an education and “belong” to the Department of Health for care. The situation of early childhood development and preschools for children with disabilities is another urgent concern, with only 28 percent of children under the age of five years accessing an early childhood development centre. What is being witnessed is policy evaporation of EWP6, resulting in a knock-on effect of under-achievement of developmental objectives for persons with disabilities in South Africa.

**Table 6: Number of children with disabilities enrolled in formal education, 2009**

Age group	Total population	Children with a disability		Enrolment in formal education (ECD centres/schools)	
		Number	Percentage	Number	Percentage
0–4 years	5 063 500	1 393 236	27.5%	389 013	27.9%
5–18 years	14 588 173	703 159	4.8%	236 154	33.6%
				Special	Ordinary
				111 619	124 535
				47.3%	52.7%

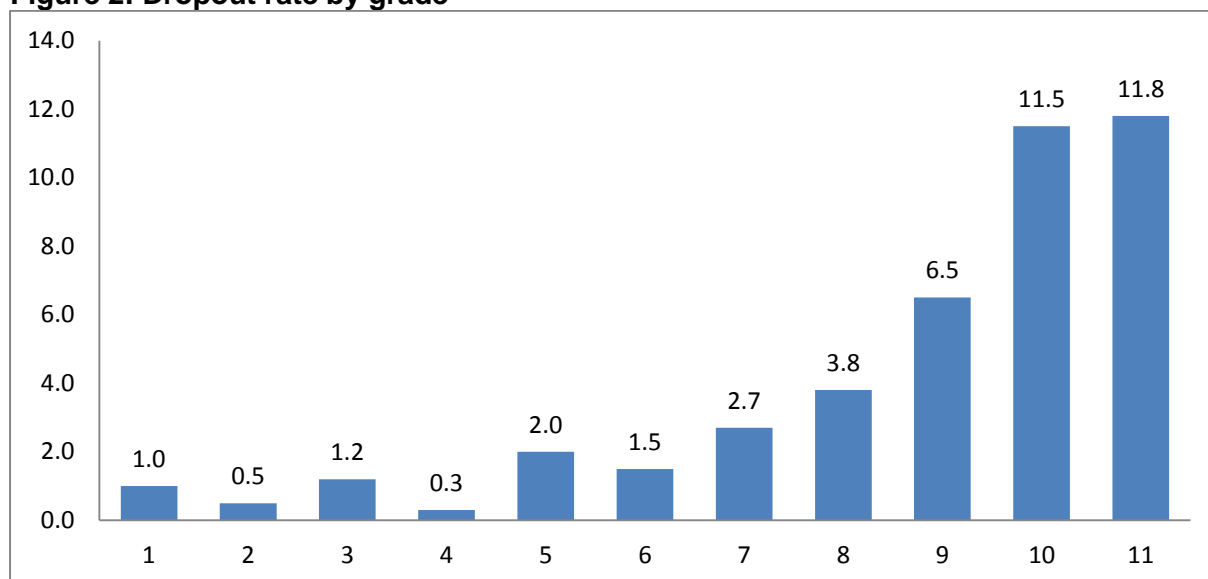
*Source: Statistics SA, 2009; Department of Basic Education, 2009*

A major challenge in educational outcomes is the drop-out rate. The 2011 summary report on macro-indicator trends in schooling concludes that the education system has achieved significant rates of participation, but lower rates of completion owing to repetition and drop-outs (see Figure 2), especially in the higher grades. Poverty is not the only reason why children do not complete their schooling years (Fleisch et al, 2010). The researchers identified other factors, such as disability, teenage pregnancy and family dynamics. This point to the need to understand and overcome learning barriers that impact negatively on overall educational outcomes.

The process of identifying and managing barriers to learning has been implemented at public schools through the establishment of district-based support teams (DBSTs) and school-based support teams (SBSTs). These structures are required to monitor, guide and support principals and schools to develop and implement intervention

strategies to overcome the identified barriers and promote effective learning and teaching in the classroom. However, the role and effectiveness of the DBSTs and SBSTs in managing learning barriers (whatever they may be) requires attention. Services need to be coordinated, outputs monitored and outcomes assessed as a collective. In 2012, the Department of Higher Education and Training entered into consultations on the Green Paper for Post-school Education and Training. The green paper acknowledges the need to develop an enabling and empowering environment across the system for staff and students with disabilities.

**Figure 2: Dropout rate by grade**



Source: National Income Dynamics Study, 2007/08

Another development unfolded during the same period in which EWP6 was being piloted. From 2002 to 2011, more public special schools were built, increasing from 375 to 423 (DWCPD, 2012) In pursuing the principle of achieving equity in access, certain provinces took the decision to build more special schools on the basis that access to special schools was denied to the majority of the population during apartheid. A 2006 survey on accessibility of ordinary schools by the Department of Education indicated that 97 percent of the over 10 000 schools surveyed provided no physical access to learners, teachers or parents who use wheelchairs. With the problem of policy evaporation of EWP6, the building of more special schools resulted in a perpetuation of the past, and the lessons learnt did not influence change at facility, community and institutional levels. Achieving equity in access to special schools has detracted both communities and government officials from keeping an eye on equality of outcomes in the educational sector.

#### **4.4 Comprehensive social security**

The NDP notes that the current model of shifting the burden of care, treatment and rehabilitation to the non-governmental sector and the poorest communities is not working and that statutory services for, among others, children and adults with



disabilities require well-conceived state and community interventions. Similar trends in institutional care for persons with disabilities, including young people with disabilities, are found where residential care facilities are seen as the right to equitable access without addressing the need for the right to family, home and community participation. Assisted and independent living programmes are limited in South Africa. Table 7 shows a stark difference in the number of care facilities in urban and rural areas, and yet the prevalence rates of disability are higher in provinces that are predominantly rural. The DSD supports residential facilities mainly through the subsidisation of these facilities, which are managed by NGOs. However, the quality of care and frequent reports of abuse in some of these residential facilities require a more stringent monitoring system.

**Table 7: Number of residents, ages and care facilities per province (2008–2011)**

	Number of residents	Number of care facilities
Urban and peri-urban	6 416	120
Rural	1 566	29
Total	7 982	149

*Source: DWCPD, 2012*

#### **4.5. Strengthening the voices of persons with disabilities through their representative organisations**

One of the major enabling factors identified in improving the lives of persons with disabilities is the strategic direction and leadership provided by an organised disability rights movement and sector. The impetus and thrust from the movement was necessary, especially during the first phase of transformation. However, interviews with the leaders of the disability movement reveal that after the first decade of democracy, there was "... a loss of momentum within the movement" (Rowland, 2001) and "... the sense of advocacy and activism which prevailed then has in my view subsided" (Masutha, 2001). Nkeli (2008) identifies a need to move more substantially from rhetoric to effective action and research.

These leaders feel that just because a "social model" of disability now prevails in the way disability is documented, it does not mean that it is being understood and addressed at grassroots level, especially in the delivery of services (Howell et al., 2006). The dual challenge of sustaining the resilience of the movement, as well as influencing a rights-based approach in policy and practice, has proven difficult. Attention was needed in recruiting and building Disabled People of South Africa in response to internal changes, because a considerable number of existing members took office in key government positions leaving local structures struggling to survive. This situation for the disability movement was not different from the challenges experienced by the wider advocacy groups and CSOs in South Africa post democracy.

A vibrant and organised disability sector, and in particular among representative organisations of persons with disabilities, is directly aligned with the call for an “active citizenry” in the NDP in order to ensure policy influence. For the disability sector specifically, it is demonstrated that without the experience and expertise of disability issues by persons with disabilities themselves, policy-makers, service providers and the public at large will remain ignorant of their needs and perpetuate the attitude of sympathy towards persons with disabilities.

#### **4.6 Meeting differing needs – adopting a developmental approach**

When referring to people with disabilities as a collective, it is well understood that citizens with a disability are not a homogenous group. The struggle of defining disability is located in the differing needs and experiences based on the type and severity of impairment, and the level and extent of attitudinal, physical and communication barriers, compounded by the demographic characteristics of age, gender, location, sexual orientation, socio-economic status, employment and marital status. If needs are to be met effectively, it is necessary to differentiate between the advocacy for disability rights to ensure oversight of legislation and policies and providing expertise and counsel on specific impairments (such as the type of assistive device most suitable for a person with a “bilateral amputation ” living in a remote rural village). Organisations representing persons with disabilities according to specific impairments (the Quadriplegics Association of South Africa, the Deaf Federation of South Africa and so on) hold valuable institutional and expert knowledge, yet require capacity to access and influence effective participatory spaces to influence disability policy.

There is adequate literature on the relationship between poverty, disability and development, identifying persons with a disability as one of the most vulnerable groups of society. Yet there is very little data and research that actually quantifies the number of persons with disabilities who are poor (Chaulken et al., 2009). Research and reports on poverty do not disaggregate for disability, and the broader discourse on economics, poverty and inequality does not define or include the scope of the problem for disability. Taylor (2002) confirms that the impact of disability is not limited to the individual affected, and that while the individual bears the brunt of illness and impairment, disability also creates hardships for those who care for and depend on disabled family members. A conservative estimate of 16 percent of South Africans is disabled or live in a household with a person who is disabled (Taylor, 2002). Discrepancies in the disability sector and inequality of outcomes between social groups, specifically urban/rural, men/women, children/youths/adults/older persons with disabilities – confirms that the strategy of targeting appropriate means testing is important to identify those most in need. Yet, policy implementation on the whole has taken on a blanket approach to addressing these priority needs. The hidden and embedded struggles of the most marginalised will continue if they are not specifically identified and managed.

With increasing awareness, knowledge and institutionalization of disability in the country, it is becoming evident that the marginalized people with disabilities need specific attention, if the high levels of inequality and poverty are to be addressed. These marginalized groups all share the quadruple burden of poverty, inequality, disability and their respective social roles, making them the most vulnerable to underdevelopment. Some of the most vulnerable groups identified are as follows:

- **Youth with disabilities** – as a component of the broader struggles of the youth sector in South Africa, the effect of poor education, unemployment and higher health risks is compounded for youth with disabilities. A recent study entitled Disabled Youth Enabling Sustainable Livelihoods found substantive inequality in outcomes between youth with disabilities and their able-bodied peers in education, employment and livelihoods.
- **Women and children with disabilities** who experience high levels of gender-based violence as well as socio-economic inequalities.
- Persons with disabilities living in rural areas – evidence presented earlier suggests that those living in rural areas are more likely to be uneducated, unemployed and to live below the poverty line than their urban counterparts.
- **Persons with intellectual and psycho-social disabilities** – with only the recent survey of 2009 identifying the number of persons with intellectual disabilities, there are limited national strategies to address their needs and a low prioritisation of resources for persons with intellectual disabilities. Effective community support and rehabilitation is lacking, resulting in continued institutionalised care.
- **Deaf persons**, whose access to opportunities and services is restricted as a result of a lack of access to education through sign language as medium of instruction, as well as interpreter services and subtitles on audio-visual broadcasts.

#### **4.7. Towards a systems approach for effective disability intervention**

The achievements discussed and the challenges highlighted are not isolated from each other. As disability moved beyond being a health issue and as the voices of persons with disabilities became clearer, the complex nature of disability unfolded over the 20 years of democracy. A small achievement in one area has the potential to greatly impact on many other dimensions of well-being, while services covering a large footprint in the country have had little positive outcome for persons with disabilities. The work of one sector is dependent on the inputs, processes and outcomes of another sector. The timing and pace of delivery, priority choices and resource allocation impact on each other to produce a web of interconnections and interrelations. The understanding and development of several functional systems within a system of disability intervention and management are critical – with disability

champions required at every level to ensure oversight and stewardship of the system.

The first country report states that the weakness in the governance machinery of the state, capacity constraints and a lack of coordination in the disability sector has detracted from a systematic approach to the implementation of the UNCRPD. The institutionalization of self-representation was an achievement to be celebrated in the disability sector; yet dependence on the strength of individuals is not sustainable without the foundation of a system of representative bodies. Disability mainstreaming as a tool is ineffective if overarching systems have not been transformed or restructured, with the necessary attention to the special and unique needs of persons with disabilities.

The mainstreaming of disability occurs on two interrelated levels. One is ensuring that the disability element is inherent in a programme or project and those persons with disabilities are included as one of the beneficiaries or target group. The other is ensuring that budget allocations provide for any reasonable accommodation measures that have to be provided when delivering universal services. The approach further locates disability as a norm rather than an exception in all policies, programmes and budgets. Mainstreaming fundamentally changes prejudicial mind-sets and applies the concept of universal design technologies and equipment.

Mainstreaming is, within the context of a rights discourse and sustainable development, about dignity, self-worth, autonomy and self-determination. It is a strategy for making the concerns and experiences of persons with disabilities an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres, so that persons with disabilities benefit on an equitable basis.

## **5. Summary and recommendations**

### **Universal access and design**

South Africa has committed itself to disability mainstreaming rather than segregation. This requires that all planned actions, including legislation, policies, budgets and programmes, in all areas and at all levels, be assessed to determine the implications for women, men, boys and girls with disabilities. It involves the integration of disability considerations into all mainstream structures, systems and processes, organisational decisions and activities, and the implementation of corrective measures (for the prevention and alleviation of prejudice, the removal of barriers, and the reduction of disparities between women and men, girls and boys – both able-bodied and disabled) in order to ultimately achieve equality.

Article 9 of the CRPD, ratified by the South African government in 2007, requires governments to undertake appropriate measures to ensure that persons with

disabilities are able to access, on an equal basis with others, the physical environment, public transport, information and communication, as well as other facilities and services open or provided to the public, both in urban and in rural areas. These measures are aimed at enabling persons with disabilities to live independently and participate fully in all aspects of life.

Universal access means the removal of cultural, physical, social and other barriers that prevent people with disabilities from entering, using or benefiting from the various systems of society that are available to other citizens. Universal access is the only way in which individuals with disabilities can enjoy equal opportunities and benefits, and join mainstream society with their families and friends. It is the key to exercising civil, political, economic, social, religious and cultural rights in society.

Universal design is the design of products, environments, programmes and services to be usable by all persons to the greatest extent possible without the need for adaptation or specialised design, including assistive devices and technologies for particular groups of persons with disabilities where these are needed.

Going forward, the country needs to prioritise the strengthening and expansion of accessibility legislation and enforcement mechanisms across all sectors to align these with the obligations contained in the CRPD.

### **Accountability and enforcement**

The polluter-pays principle should apply when public and private institutions flout constitutional entitlements and legislation that protect and promote the rights of persons with disabilities. Government departments, Parliament, provincial legislatures and Chapter 9 institutions need to strengthen their oversight roles in the field of disability. This requires the following:

- Strengthening existing planning, monitoring and evaluation systems to track and report on inequalities and incidences of the infringement on rights of persons with disabilities across the government-wide planning, delivery, monitoring and evaluation systems.
- Reviewing existing transversal, as well as sector legislation, to strengthen the prevention of discrimination against persons with disabilities, as well as enforcement when discrimination does occur.
- Strengthening the capacity of organisations of persons with disabilities to advocate for the rights of persons with disabilities, and to monitor and act upon incidents of disability rights' infringements.

### **Partnership**

The right to live independently and to be included as an equal citizen in one's community requires partnerships between all sectors of society. Public-sector institutions and service organizations need to align their services at community level to provide the seamless support services required to realize this right. Organs of civil society need to become active agents of change in fighting discriminatory attitudes and belief systems that push persons with disabilities and their families to the margins of society. Organizations of persons with disabilities, as the representative

voice of persons with disabilities, need to strengthen their footprint at a local level to empower persons with disabilities, to advocate for change, and to monitor and act upon rights infringements.

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