

REPUBLIC OF SOUTH AFRICA

FROM POLICY TO ACTION: INSTITUTIONALISING SELF-REPRESENTATION FOR PERSONS WITH DISABILITIES

EXPLANATORY NOTE

Purpose

- The purpose of this framework is to provide for a statutory and regulatory reference and approach for the promotion and upholding of the right to self-representation by and for persons with disabilities in South Africa.
- To provide a framework for an integrated and multi-disciplinary coordination of the right to self-representation and support
- To provide for the establishment of consultative platforms/committees and national and provincial forums and related institutions to promote self-representation
- To prevent and combat discrimination and secondary victimization of persons with disabilities by providing early intervention and reintegration programmes into society through institutionalization of selfrepresentation to enhance the representative voice of persons with disabilities
- To provide for designation and deployment strategy on consultative and decision making platforms
- To provide for empowerment and support services for persons with disabilities to ensure non-discrimination and representation at a socioeconomic, political, civil, cultural and social participation aspects of life
- To provide for the development and implementation of selfrepresentation through norms and minimum standards.
- To provide for the specific roles and responsibilities of relevant government departments and other stakeholders; And to provide for matters connected there with, for purposes of legal recourse

Preamble

Whereas-the framework relates to alignment of the White Paper on the Rights of Persons with Disabilities with legislation related to the right to self-representation by persons with disabilities

Whereas-the bill of rights in the Constitution of the Republic of South Africa 1996 provides that "everyone has the right amongst others to human dignity and equality before the law

Whereas- the United Nations Convention on the Rights of Persons with Disabilities provides for a declaration of basic principles of self-representation and justice for persons with disabilities to prevent abuse of power;

Whereas-the United Nations Convention on the Rights of Persons with Disabilities urges all state parties through its general obligations to enact appropriate legislation to promote self-representation as an absolute right for persons with disabilities

Whereas- the Republic of South Africa is a signatory to and has ratified the United Nations Conventions on the Right of Persons with Disabilities and all declarations of human rights

Whereas- the Republic of South Africa has since 1994 become an intergral an accepted member of community of nations and is committed that persons with disabilities have the right to self-representation and are at the epicentre of the justice system and process

Whereas-the Republic of South Africa recognises the right of and for self – representation for persons with disabilities by ensuring that the general provisions of legal recourse are effective, integrated, multi-disciplinary, supportive and that the empowerment of persons with disabilities towards self-representation is a permanent feature at a policy and legislation level and;

Whereas- it is necessary to combat and prevent tertiary, secondary and primary discrimination of persons with disabilities for the progressive realisation of the right to self-representation

BE IT THEREFORE APPROVED BY THE CABINET OF THE REPUBLIC OF SOUTH AFRICA

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CHAPTER 1: SELF-REPRESENTATION

Interpretation, Objectives and Application of the Framework

1.1 Abbreviations

ADP	Protocol to the African Charter for Human and Peoples' Rights on		
	the Rights of Persons with Disabilities (Africa Disability Protocol)		
CBR	Community-Based Rehabilitation		
CAT	Convention Against Torture and other Cruel, Inhuman or Dec		
	Treatment or Punishment		
CEDAW	Convention on the Elimination of All Forms of Discrimination		
	Against Women (1979);		
CRC	Convention on the Rights of the Child		
CERD	International Convention on the Elimination of All Forms of Racial		
	Discrimination (1966).		
CSOs	Civil Society Organisations		
DPOs	Disabled Peoples' Organisations		
INDS	1997 White Paper on an Integrated National Disability Strategy		
ICCPR	International Covenant on Civil and Political Rights		
ICESCR	International Covenant on Economic, Social and Cultural Rights		
PEPUDA	Promotion of Equality, Prevention of Unfair Discrimination Act		
NBAC	National Bid Adjudication Committee		
RBAC	Regional Bid Adjudication Committee		
RDP	Reconstruction and Development Programme		
SABC	South African Broadcasting Corporation		
SAHRC	South African Human Rights Commission		
UNCRPD	UN Convention on the Rights of Persons with Disabilities		
WHO	World Health Organisation		
WPRPD	White Paper on the Rights of Persons with Disabilities		

1.2 Definitions and Interpretations

- Advocacy: The political act or process of supporting a cause, idea or policy by individuals or a group/s with an aim to influence the outcome. Advocacy should ensure that affected peoples voices are heard, their rights are promoted and that their views are considered when decisions that impact directly on their lives are being made.
- Assistive devices: Any device, product, equipment or tool that is designed or adapted to enable persons with disabilities to participate in activities, tasks or actions. They may include: (i) mobility aids such as wheelchairs, prostheses and crutches; (ii) Communication aids such as hearing aids, FM systems; (iii) Sensory aids such as white canes; noise reducing headphones and coloured lenses (iv) Technology aids such as computers for alternate and augmentative communication, screen readers, magnifiers, text in audio format.
- Assistive technology: It is an umbrella term that includes assistive, adaptive, and rehabilitative devices and services for persons with disabilities, which enable persons with disabilities and learning differences to attain independence. They include for example, loop systems, sub texting and alternative input for cognitive assistance and computer or electrical assistive devices.
- **Disability:** The UNCRPD does not attempt to define disability per se, but rather recognises disability as an evolving concept. Disability is imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments.
- **Discrimination**: Discrimination is any act or omission, including a policy, law, rule, practice, condition or situation which directly or indirectly (a) imposes burdens, obligations or disadvantages on; and/or (b) withholds benefits, opportunities or advantages from, any person on one or more of the prohibited grounds, which include disability and any other ground that might disadvantage a person, undermines human dignity or adversely affects an individual's rights and freedoms.

- **Disability Discrimination**: Discrimination on the basis of disability means any distinction, exclusion or restriction of persons on the basis of disability, which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, on all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. It encompasses all forms of unfair discrimination, whether direct or indirect, including denial of reasonable accommodation.
- Self-Representation: refers to the practice of people being able to articulate their own issues by themselves and for themselves. It refers to people being enabled and allowed to have their own voice in issues that relate to their specific needs and circumstances¹.
- Equality of arms: is the guarantee that both sides will be given the same procedural opportunities to prove their cases.
- Accusatorial system: is the right to direct confrontation as one of the essential ingredients in a fair trial.
- **Compounded vulnerability:** Environmental as well as personal contexts can lead to compounded vulnerability to exclusion and human rights violations for persons with disabilities. These contexts could range from gender, race, impairment, where people live, socio-economic status, age, qualification levels, cultural beliefs, health status and others.

¹ Government of South Africa, White Paper on the Rights of Persons with Disabilities (WPRPD), 9 December 2015.

1.3 Objectives of the Framework

The objectives of this framework are to move from policy to action/ institutionalising self-representation for persons with disabilities by focusing on the following work:

- a Strengthening access and participation through self-representation;
- b Official recognition of representative organizations of and for persons with disabilities (inclusive of parent organizations);
- c Strengthening diversity and self-advocacy programmes for persons with disabilities (taking into consideration intersectionality issues);
- d self-representation in public life;
- e Constitutional and legal imperatives towards an obligation to legislate the right to self-representation.

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.

The principle of self-representation has resulted in a number of other significant policy trajectories. For instance, **the strengthening of the disability movement** developed into a priority as there was a need to ensure that they are active participants in the policy value chain. 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 National Development Plan (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.**

Self-representation of also a key ingredient for **meeting differing needs through a developmental approach.**

The Self-Representation Framework (SRF) is a component of the White Paper on the Rights of Persons with Disabilities (WPRPD) as described in Strategic **Pillar 1: Removing Barriers to Access and Participation and Strategic Pillar 6: Strengthening the Representative Voice of Persons with Disabilities.**

1.4 Application of the Framework

1.4.1 The Legal Application of the Framework

This Framework applies to duty-bearers, including oversight institutions, government institutions, the judiciary, the private sector, the media, law and policy makers, public servants, frontline staff, as well as representative organisations of persons with disabilities (inclusive of parents' organisations), non-governmental organisations and civil society organisations (CSOs).

The Framework as aimed at achieving **inclusion** and strengthening **access and participation** through **self-representation**; providing **official recognition of representative organizations** of and for persons with disabilities (inclusive of parent organizations); **strengthening diversity and self-advocacy programmes** for persons with disabilities (taking into consideration intersectionality issues); **facilitating and promoting self-representation in public life** and in **increasing awareness of constitutional and legal imperatives** towards an obligation to legislate the right to self-representation.

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.

The framework is a policy guideline or instrument that provides a **detailed analysis** of matters, principles and approaches to self-representation in process, events or other environments that require participation, mainstreaming/ inclusion (or *'involvement'*) of the needs of persons with disabilities in specific sectors of government, life and generally in society.

The crosscutting nature of self-representation and inclusion strategies requires that the **principles and provisions of the framework apply to all sectors** of society/ all tiers of government, social/economic/human rights/political structures and their strategies.

The mandate for this framework is taken from the Bill of Rights of the Constitution of the Republic of South Africa. **The right to equality guaranteed in the 1996 Constitution includes social and political equality** at all levels. This means, in part, that persons with disabilities should enjoy equal access to fundamental rights, even if the exercise of these rights involves removing barriers and creating enabling mechanism. For example:

- a. the right to vote is restricted by inaccessible polling booths and voting material;
- b. the right of access to public information is restricted as a result of inaccessible public media;
- c. failure to recognise Sign Language prevents Deaf people from enjoying access to full participation in the social, political and economic life of the country.

1.4.2 South African Legal Context

Brief Analysis of Post-1994 Disability Policy Formulation Milestones

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 Charter, founded on the principles enshrined in the 1955 Freedom Charter, informed, and continues to inform, the promotion and protection of the rights of persons with disabilities in South Africa.

The Integrated National Disability Strategy (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 government².

The INDS was informed by the United Nations Standard Rules for the Equalisation of Opportunities for Persons with Disabilities (United Nations, 1994) and the Disability Rights Charter. It 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 rightsbased 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

² DSD Country report (2015)

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.

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 were needed to address disability issues³.

Table 1 below shows legislation legislation, policies, conventions and guidelines pertaining to people with disabilities in South Africa since 1994.

Table 1: Significant legislation, policies, conventions and guidelines pertaining to people with disabilities in South Africa

1994–2000	2001–2006	2007–2012		
National legislation				
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) Housing Act (1997)	Code of Good Practice for the Employment of Persons with Disabilities (2002)	Children's Amendment Act (2007)		
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)				
International legislation				

³ Ibid

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

The period 2001 to 20012 entrenched disability rights in government legislation. 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 disabilities⁴.

The ensure that these historical/contemporary policy values are entrenched in all sector-wide policies, legislation and strategies such as the NDP, the South African government adopted the White Paper on the Rights of Persons with Disabilities (WPRPD). The WPRPD reiterates that the primary responsibility for disability equity lies with national, provincial and local government; and other sectors of society but also allocates responsibilities to persons with disabilities and their families. The vision of the WPRPD is the creation of free and just society inclusive of all persons with disabilities as equal citizens".

The WPRPD commits duty bearers to realising the rights of persons with disabilities by (among other measures):

- Updates South Africa's 1997 White Paper on an Integrated National Disability Strategy (INDS),
- Integrates obligations of the UN Convention on the Rights of Persons with
- Disabilities (UNCRPD) and in the Continental Plan of Action for the African Decade of Persons with Disabilities (both of which South Africa has signed), with South Africa's legislation, policy frameworks and the National Development Plan 2030,
- Endorses a mainstreaming trajectory for realising the rights of persons with disabilities,
- Provides clarity on and guides the development of standard operating procedures for mainstreaming disability,

⁴ The Presidency, Twenty-review South Africa (1994-2014): Background Paper: Disability

- Guides the review of all existing, and the development of new, sectoral policies, programmes, budgets and reporting systems to bring these in line with both Constitutional and international treaty obligations,
- Stipulates norms and standards for the removal of discriminatory barriers that perpetuate the exclusion and segregation of persons with disabilities,
- Broadly outlines the responsibilities and accountabilities of the various stakeholders involved in providing barrier-free, appropriate, effective, efficient and coordinated service delivery to persons with disabilities, and
- Guides self-representation of persons with disabilities⁵.

The White Paper recognises self-representation in:

- a Strategic Pillar 1: Removing Barriers to Access and Participation and Strategic
- b Strategic Pillar 6: Strengthening the Representative Voice of Persons with Disabilities
- c Strategic Pillar 7: Building a Disability Equitable State Machinery

The approach adopted for the framework highlights three (3) pillars, namely; rights, empowerment and equality as follows:

a) The Rights Pillar - A 'rights-based' pillar essentially argues that all people are entitled to universal human rights and development should be oriented to meeting those rights. A series of international human rights treaties and other instruments adopted since 1945 have conferred legal form on inherent human rights and developed the body of international human rights. Other instruments have been adopted at the regional level reflecting the particular human rights concerns of the region and providing for specific mechanisms of protection. Respect for human rights requires the establishment of the rule of law at the national level.

With a rights-based approach, effective action for development moves from the <u>optional</u> realm of charity into the <u>mandatory</u> realm of law, with identifiable rights, obligations, rights-holders and duty-bearers.

The Empowerment Pillar: The empowerment approach is therefore identified as a core pillar for enabling this targeted group to avail to and access those opportunities that exist. It also includes encouraging, and developing the skills for self-sufficiency, with a focus on eliminating the need for charity or welfare in the individuals of the group

The Equality Pillar – The aim of equality is to focus on equalising the opportunities and life chances that are available, to persons with disabilities. It signifies an aspiration to work towards a society in which persons with disabilities are able to

⁵ White Paper on the Rights of Persons with Disabilities (WPRPD)

live equally fulfilling lives and to equally contribute to designing the society that they want.

1.4.3 Examples of the South African Policy Environment on Disability and Self-Representation

a. Public Works Department: Disability Policy Guideline

The principles guiding the implementation of the Department's Policy Guideline on Disability is in keeping with the imperatives of the constitution, the UNCRPD, Promotion of Equality, Prevention of Unfair Discrimination Act (PEPUDA), Integrated National Disability Strategy (INDS), Batho Pele Principles, and other related policies. These principles are:

- 1. Self-representation to ensure the involvement of persons with disabilities and their organisations to attain the successful implementation of this Policy Guideline.
- self-representation: persons with disabilities be included in the National Bid Adjudication Committee (NBAC) and Regional Bid Adjudication Committee (RBAC)
- 3. Facilitate the representation of persons with disabilities in the Bid Specification/ Evaluation Committees.

b. Disability Policy Western Cape

People with Disabilities have the right to self-representation in processes and structures of decision-making on issues that affect them. In situations where they cannot represent themselves, they have the right to choose/nominate a **family member to represent themselves**.

The right to self-representation is reinforced in this Policy on Disability in the sections entitled Roles and Responsibilities, Approach, Structures for Implementation and Monitoring and Evaluation. Some examples of entry points for applying the principle of self-representation are **programme or project conceptualisation and design; consultation processes; and participation in ad-hoc task teams.**

Self-respect and self-sufficiency: It is critical that all assistance and support provided to People with Disabilities is done with **their full consent and inclusion** (self-representation as described above). The purpose and outcome of the assistance and support is that of self-respect and self-sufficiency. In other words, all projects and activities should facilitate, as far as is possible and feasible, independent living – from the meeting of personal needs to that of participating in social and economic life.

- **c.** Self-representation on SABC Board: People with disabilities are best equipped to change perceptions and attitudes towards disability, and should therefore play a central role in the development of strategies and projects through their legitimate organisations. The appointment of a person with disability to the SABC Board (1996/97) was an important first step.
- d. Self-representation-Transport Services: People with disabilities experience problems arising from the lack of barrier free access on an almost daily basis. It is, however, important to ensure that advice is sought from the legitimate representatives of disabled people's organisations to ensure that a representative and not a personal viewpoint is obtained. Different disability populations have different public transport needs. There are also differences in the needs of people living in rural and urban areas. It is therefore essential that processes to develop accessible commuter systems include participation by all stakeholders.
- e. Social Welfare Services: Social welfare services should include a range of strategies designed to facilitate access by people with disabilities and parents of disabled children to mechanisms which will enhance their ability to live independently. Self-representation can be on management structures of either residents or their families or advocates.
- **f. Education Sector**: can facilitate a process to develop inclusive strategies that facilitate self-representation of students with disabilities as a distinct constituency on all forums and governance structures.

1.5 International Legal Context

Introduction

South Africa has been a key role prayer in the development of international disability policy instruments. Substantial historical milestones have now been gathered in an attempt to achieve and guarantee the rights of persons with disabilities. It is worth noting that persons with disabilities **actively and successfully participate**d in the development of international, regional and national policy instruments.

Self-Representation played and continue to play a crucial role in the development, implementation, monitoring and evaluation on public/private sector and CSO policies/strategies.

Key international policy instruments on disability include:

a General International Norms Pertaining to Persons with Disabilities

The Charter of the United Nations requires member States to respect human rights for all without any distinction as to race, sex, language or religion and forms the nucleus for the protection of rights for persons with disabilities.

Specific articles of the Charter provide the foundation on which disability rights can be built. These articles are as follows:

- Article 1 (3) states that the purpose of the United Nations is "...to achieve international co-operation in solving international problems of an economic, social, cultural, or humanitarian character, and in promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction ".
- Article 13 (1) (b) states that the General Assembly "...shall initiate studies and make recommendations for the purpose of promoting international cooperation in the economic, social, cultural, educational, and health field, and assisting in the realisation of human rights and fundamental freedoms for all "
- Article 55 (a) states that the "... United Nations shall promote higher standards of living, full employment, and conditions of economic and social progress and development." Furthermore, article 55 (c) provides that the "... United Nations shall promote universal respect for, and observance of, human rights and fundamental freedoms for all."

The Universal Declaration of Human Rights forms the fundamental normative basis on which international norms and standards concerning persons with disabilities have evolved. The Universal Declaration contains a number of provisions, which constitute the foundation for resolutions regarding disabilities based on the principle of equal rights.

Apart from the Universal Declaration of Human Rights there are six core human rights conventions that relate to the rights of persons with disabilities. The International Covenant on Civil and Political Rights (ICCPR), and the International Covenant on Economic, Social and Cultural Rights (ICESCR) ratified in 1966 are the two basic human rights treaties and together with the Universal Declaration of Human Rights constitute the International Bill of Rights. The other four core human rights conventions are the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)(1949); the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979); the Convention on the Rights of the Child (CRC) (1989); and the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) (1966). While all six conventions stipulate the principle of non- discrimination, the lastmentioned treaties specify the general rights enunciated in the ICCPR and ICESCR.

The provisions on anti-discrimination in the ICCPR have special relevance to rights of persons with disabilities. One of the most important rights in relation to persons with disabilities is enunciated in article 25, which establishes that citizens are entitled to *"access on general terms of equality, to public service in his country".*

General Comment No. 5 is a definitive analysis of the States parties' obligations under the ICESCR in the context of disability. It recognizes that:

"[t]through neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services." (para. 15)

States parties are encouraged to take affirmative action to:

"reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities." (para. 9) Further, states parties are, "required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability." (para. 5)

The General Comment No. 5 also states that, "it is also necessary to ensure that support services, including assistance devices are available for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights." (para. 33)

Unlike other human rights conventions, the Convention on the Rights of the Child in article 23 focuses directly on children with disabilities. Even though no direct obligations have been placed on State Parties to take measures to ensure that children with disabilities enjoy a life of dignity, self-reliance and integration with the community, article 23, paragraph 1-4 recognizes the importance of participation in the community, education, training health care, rehabilitation employment and recreation opportunities for children with disabilities. The Committee on the Rights of the Child has however established that the fact that article 23 is dedicated to children with disabilities should not mean that the rights of children with disabilities are confined to that article.

In the past few decades, the United Nations has given considerable attention to the rights of persons with disabilities. Increased crisis situations such as widespread hunger, wars, and ecological disasters afflicting many communities around the world have increased the numbers of persons with disabilities. Apart from general human

rights conventions, the United Nations has created extensive policy on issues of disability albeit at times using a medical model rather than human rights approaches. In 1971, the Declaration on the Rights of Mentally Retarded Persons was adopted by the General Assembly. Article 1 of the Declaration on the Rights of Mentally Retarded Persons proclaims that mentally retarded persons have the same rights as other human beings.

Article 1 of the Declaration on the Rights of Disabled Persons adopted in 1975, in its preamble, the General Assembly called for "...national and international action to ensure that it will be used as a common basis and frame of reference for the protection of [the rights contained within the Declaration] " Article 4 asserts broad social and economic rights for disabled persons and provides that disabled persons have the same civil and political rights as other human beings. Article 5 provides that "...disabled persons are entitled to the measures designed to enable them to become as self- reliant as possible." Article 6 states that persons with disabilities have the "...right to medical, psychological and functional treatment (...) to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration." Article 7 provides that disabled persons have the right to economic and social security and to a decent level of living. "Disabled persons are entitled to have their special needs taken into account at all stages of economic and social planning" (article 8). Also, Article 9 states that disabled persons have the right "...to live with their families or with foster parents and to participate in all social, creative or recreational activities."

The Declaration also prohibits discrimination. For example, article 10 states: "Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature." The Declaration further requires that disabled persons be "...provided with qualified legal aid where such aid is indispensable for the protection of disabled persons themselves and their property" (article 11). Finally, the Declaration states that persons with disabilities and their families have a right to receive information on the rights contained in the Declaration (article 13).

In the 1980's the activity that began in the 1970's picked up momentum and the next decade witnessed an acceleration of activity on rights on behalf of persons with disability. The year 1981 was declared the *International Year of Disabled Persons* by a General Assembly resolution 31/123 of 16 December 1976. An important United Nations Voluntary Fund on Disability was established by General Assembly Resolution 32/133 in connection with the International Year of Disabled Persons. The Fund was later renamed the *Voluntary Fund for the United Nations Decade of Disabled Persons* (1983-1992). The theme was *Full Participation and Equality*, defined as the right of persons with disabilities to participate fully in

their societies, to enjoy equal living conditions, and to have an equal share in improved conditions.

The resolution proclaimed that the year 1981 be devoted to the full integration of disabled persons in society; the encouragement of academic research projects to facilitate the participation of persons with disabilities in daily life; the education of the public in regard to the rights of persons with disabilities; *understanding and accepting persons with disabilities; and encouraging persons with disabilities to form organizations to express their views.*

One of the most important outcomes of the *International Year of Disabled Persons* was the formulation of the *World Programme of Action Concerning Disabled Persons, which was adopted by the General Assembly in 1982.* The World Programme represents the first worldwide international long-term policy in relation to disabled persons. The Programme proposed three actions:

- 1. Prevention of mental, physical and sensory impairments;
- 2. Rehabilitation to assist disabled persons to reach their optimum mental, physical, and social capacities;
- 3. Equalization of opportunities for persons with disabilities in areas including housing, transportation, education, social and medical well-being and recreation.

The purpose of the World Programme is to promote effective measures for prevention of disability, rehabilitation and the **realisation of the goals of Full Participation of disabled persons in social life and development and of** *Equality*. The Programme adds a human rights dimension by recognising the Equalization of Opportunities as an important objective for achieving full participation by disabled persons in all areas of life.

The Programme marks a shift towards a **rights-based model** and an explicit recognition of the right of all persons to equal opportunity. In paragraph 12, the WPA defines "equalization of opportunities" as, "the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all".

The General Assembly adopted the resolution **Implementation of the World Programme of Action Concerning Disabled Persons** the year following the adoption of the World Programme.

The General Assembly declared **the period of 1983 to 1992 the** *United Nations* **Decade of Disabled Persons.** The General Assembly encouraged Member States to use the decade to implement the World Programme of Action. In 1989,

the General Assembly adopted the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability. The Guidelines provide a framework for the education and employment of persons with disabilities within government ministries and on all levels of national policy-making. The aim of the Tallinn Guidelines is to promote the human resources development of persons with disabilities. Guideline 6 states that human resource development "...is a process centred on the human person that seeks to realise the full potential and capabilities of human beings." Guideline 9 provides that "...the abilities of disabled persons and their families should be strengthened through community-based supplementary services provided by Governments and non-governmental organizations."

The Guidelines outline a series of strategies for promoting the human resource development of persons with disabilities. These strategies include the promotion of education, training and employment for disabled persons, as well as community awareness. In particular, guideline 33 provides that "...disabled persons have the right to be trained for and to work on equal terms in the regular labour force." Guideline 23 states that "...education at the primary, secondary and higher levels should be available to disabled persons within the regular educational system and in regular school settings, as well as in vocational training programmes." Guideline 28 provides that "...in addition to being offered formal skills training and education, disabled persons should be offered training in social and self-help skills to prepare them from independent living." The thrust of the guidelines is that disabled persons are "...agents of their own destiny rather than objects of care..." (Guideline 8).

In 1991, the General Assembly adopted the Principles for the Protection of Persons with Mental Illness for the Improvement of Mental Health Care. The Principles define the basic rights and fundamental freedoms of persons with disabilities and was considered a new development in the field of treatment of mental health. The Principles represent minimum United Nations standards for protecting the fundamental freedoms and legal rights of those with mental illness. They are intended to be used by Governments, special agencies, national and regional organizations, international organizations, and non-governmental organizations as a guide.

The major outcomes of the last decade were the designation of December 3rd as the annual *International Day of Disabled Persons* (General Assembly Resolution 48/98 of 20 December 1993) and the subsequent adoption of **The Standard Rules on the Equalization of Opportunities for Persons with Disabilities**. The Standard Rules consist of four major sections: 1) **Preconditions for equal participation; 2) Target areas for equal participation, 3) Implementation measures; and 4) Monitoring mechanisms.** The Rules summarise the message of the World Programme of Action concerning Disabled Persons and are designed to provide Governments with policy guidelines and options, which can be incorporated into national legislation. The long-term strategy presents a framework for collaborative action at the national, regional and international levels to achieve the aim expressed by the Assembly in resolution 48/99 of a society for all by the year 2010. The Strategy outlines a sequence of suggested actions by interested Governments for the period 1995-2010, together with associated targets, time-frames for action and an ancillary set of support measures at the regional and international levels to realize that aim.

Although the Standard Rules on the Equalization of Opportunities for Persons with Disabilities are not legally binding and do not have the full force of law, they have been adopted by a large number of States and imply a strong moral and political commitment on behalf of States to take action for the equalization of opportunities for disabled persons. The Standard Rules is, in fact, the **first universal instrument to refer specifically to persons with disabilities, as well as to contain an extremely broad statement of the rights to equal opportunities**.

The second chapter of the Standard Rules deals with *Target Areas for Equal Participation* (rules 5 to 12). The selected target areas include accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.

To attain independence, appropriate employment for disabled persons is essential. As stated in Rule 7 of the Standard Rules, "States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment." One of the key aspects in social policy reform in recent years has been the recognition that disabled persons have been excluded from access to employment in the public and private sector for reasons unrelated to their ability to do the job. Rule 7 (1) provides that employment laws "...must not discriminate against persons with disabilities and must not raise obstacles to their employment."

Rule 9 (2) encourages States to promote the full participation of persons with disabilities in family life. In particular, persons with disabilities must not be denied the opportunity to express their sexual identity and experience parenthood. Rules 10 - 12 require States to ensure that people with disabilities have equal opportunities to participate in cultural activities, recreation and sports, and religious life. True equalization of opportunities means that disabled persons are ensured equal participation in all areas of life, including cultural, recreational, sports, and religious life.

Chapter III of the Standard Rules stipulates the various implementation measures for States to follow. States are responsible for, among other measures:

- a. Creating the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities (rule 15);
- b. Financing national programmes and measures to create equal opportunities for persons with disabilities (rule 16);
- c. Establishing and strengthening national co-ordinating committees to serve as a national focal point on disability matters (rule 17);
- d. Recognising the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels (rule 18);
- e. Participate actively in international co-operation concerning policies for the equalization of opportunities for persons with disabilities (rule 22).
- f. Rule 15 of Chapter III deals explicitly with legislation. It provides: "States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities."

b. UN Convention on the Rights of Persons with Disabilities (UNCRPD)

South Africa ratified the **UN Convention on the Rights of Persons with Disabilities and its Optional Protocol** without reservation in 2007. The Convention states, in part, that:

- (k) Concerned that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,
- (m) Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,
- (o) Considering that persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programmes, including those directly concerning them.

Key articles of the CRPD related to participation and self-representation:

Article 3 of the CRPD entitled General principles

(c) Full and effective participation and inclusion in society;

Article 4 General obligations

- (e) To take all appropriate measures to **eliminate discrimination** on the basis of disability by any person, organization or private enterprise;
- (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development standards and guidelines;
- (g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
- (h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities⁶.
- 3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 7 Children with disabilities

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right⁷.

Article 12 Equal recognition before the law

- 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

⁶ UN CRPD Article 4

⁷ Ibid

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.

Article 13 Access to justice

- 1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
 - 2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 19: Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

Article 21 Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention⁸.

Article 27: Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions.

There is a provision for self-representation in Public Life.

Article 30: Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life⁹.

Article 33: National implementation and monitoring

4 Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process¹⁰.

Article 34 Committee on the Rights of Persons with Disabilities

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities¹¹.

1.5.1 Self-Representation at Continental Level Using African Union (AU) Policy Instruments

The rights of persons with disabilities have been recognised in Africa's seminal human rights instrument, the 1981 African Charter on Human and Peoples' Rights¹² (African Charter), at the generic and specific levels. This recognition is also present in Africa's other key human rights instruments.

Article 2 of the African Charter provides that:

'Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.'¹³

Article 2 of the 2006 Youth Charter provides that:

State Parties shall recognize the rights of Young people from ethnic, religious, and linguistic marginalized groups or youth of indigenous origin, to enjoy their own culture,

⁹ Ibid

¹⁰ Ibid

¹¹ UN CRPD Article 29

¹² Organization of African Unity, *African Charter on Human and Peoples' Rights ("Banjul Charter")*, 27 June 1981, CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), available at:

http://www.unhcr.org/refworld/docid/3ae6b3630.html [accessed 12 March 2012] Entry into force: 21 October 1986

¹³ Ibid

freely practice their own religion or to use their own language in community with other members of their group.¹⁴

Article 13 of the Children's Charter provides that:

'2. States Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, of assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development'.

Article 8 of the Charter on Democracy, Elections and Governance (Democracy Charter) provides that:

'1. State Parties shall eliminate all forms of discrimination especially those based on political opinion, gender, ethnic, religious and racial grounds as well as any other form of intolerance.

2. State Parties shall adopt legislative and administrative measures to guarantee the rights of women, ethnic minorities, migrants, people with disabilities, refugees and displaced persons and other marginalized and vulnerable social groups'.¹⁵

Article 31 of the Democracy Charter states:

'1. State parties shall promote participation of social groups with special needs, including the Youth and people with disabilities, in the governance process.

2. State parties shall ensure systematic and comprehensive civic education in order to encourage full participation of social groups with special needs in democracy and development processes'.¹⁶

In the Protocol to the African Charter on Human and Peoples' Rights of Persons with disabilities (Africa Disability Protocol or ADP) Rights Article 2: General Obligations states that:

'States Parties shall take appropriate and effective measures, including policy, legislative, administrative, institutional and budgetary steps, to ensure, respect, promote, protect and fulfil the rights and dignity of persons with disabilities, without discrimination on the basis of disability, including by

¹⁴ African Union, *African Youth Charter*, 2 July 2006, available at:

http://www.unhcr.org/refworld/docid/493fe0b72.html [accessed 12 March 2012] Entry into Force: 08 August 2009

¹⁵ African Union, African Charter on Democracy, Elections and Governance, 30 January

^{2007,} available at: http://www.unhcr.org/refworld/docid/493fe2332.html [accessed 12 March 2012]. Entry into force: 15 February 2012

¹⁶ Ibid

j. Closely consulting and actively engaging persons with disabilities and their representative organisations in implementation of the Protocol'.

The right to **participation and self-representation** is recognised and affirmed in the ADP:

Article 17: Right to Participate in Political and Public Life

- 1. Every person with a disability has the right to participate in political and public life.
- 2. States Parties shall take all appropriate policy, legislative and other measures to ensure this right, on the basis of equality, including through:
- a. Undertaking or facilitating systematic and comprehensive civic education to encourage full participation of persons with disabilities in democracy and development processes, including by ensuring civic education materials are availed in accessible formats;
- b. Ensuring that persons with disabilities, including persons with psychosocial disabilities and intellectual disabilities, can effectively participate in political and public life, including as members of political parties, electors and holders of political and public offices;
- c. Putting in place reasonable accommodation and other support measures consistent with the secrecy of the ballot, including as appropriate, by ensuring accessibility to polling stations and facilitating assisted voting, for persons with disabilities to enable their effective participation in political and public life;
- d. Realising increased and effective representation and participation of persons with disabilities on an equitable basis as members of regional, sub-regional, national and local legislative bodies;
- e. Repealing or amending laws that on the basis of disability restrict the right of persons with disabilities to vote, stand for or remain in public office.

2. PROCESS TOWARDS OFFICIAL RECOGNITION OF REPRESENTATIVE ORGANIZATIONS OF AND FOR PERSONS WITH DISABILITIES (INCLUSIVE OF PARENT ORGANIZATIONS)

Introduction

The Irene declaration of the national disability rights summit¹⁷ was adopted by all stakeholders (disabled people organisations, parents organisations, disability service organisations, national and provincial government departments, municipalities, institutions promoting democracy, non-governmental organisations, institutions of

¹⁷ DSD Disability Rights Summit 2016 10-12 March 2016

higher and further education, and international development agencies. The declaration, in part, resolved that:

- 1. Persons with disabilities in South Africa however continue to experience unacceptably high levels of exclusion, marginalisation and discrimination;
- 2. Children and adults with disabilities live in every community, and must therefore be visible in every playground, early childhood development centre and programme, school, college, university, place of work, sportsground and place of worship;

The declaration further states that:

- 3. The collection of evidence that demonstrate access and participation by persons with disabilities to opportunities and services, is central to enable reporting on progress in reducing inequality and poverty experienced by persons with disabilities;
- 4. The right to self-representation by persons with disabilities on matters affecting their lives, is enshrined in the Constitutional values of freedom of association as well as the UNCRPD;
- 5. Only representative organisations of persons with disabilities can represent persons with disabilities and must be accountable to their constituencies;
- 6. The right to equal recognition before the law for all persons, regardless of severity of impairment or geographical location, is enshrined in our Constitution and also an obligation contained in the UN Convention on the Rights of Persons with Disabilities;
- 7. Further engagement is required between key stakeholders on the interpretation of Article 12 (of the CRPD), and the engagement process needs to affirm the principle of self-representation by rights-holders;
- 8. The WHO Community-Based Rehabilitation (CBR) matrix provides a sound basis from which to plan community based disability-specific services, and must **be implemented within the social model of disability, placing representative organisations of persons with disabilities** at the centre of decision-making;

In order for DPOs to enjoy (governmental/other) support for the development and strengthening of their role in the planning and implementation of public policies and programmes, the following *Priority Actions* are recommended: Member States:

- a. To promote and facilitate the establishment of DPOs at local and national levels in order to support PWD empowerment;
- b. To establish and resource a national Civil Society Organisation/DPO fund;
- c. To promote and facilitate the establishment of National Federations of Disabled Persons Organizations;

d. To promote and facilitate through financial support, local and national representation of persons with disabilities in all decision-making structures.

2.1 1997 White Paper on an Integrated National Disability Strategy (INDS)

The paradigm shift (from the medical to the social model) has come about largely through the development of strong Disabled Peoples' Organisations (DPOs). Central to the concept of the social model of disability is the principle of self-representation by people with disabilities through DPOs.

It is also important that people with intellectual or severe mental disabilities are able to speak for themselves through the use of advocates. The South African Federation for Mental Health has embarked on an advocacy programme to develop the concept of self-representation by people with severe mental and/or intellectual disabilities.

The principles upon which the Strategy is based include:

- a. A People-Driven Process
- b. A fundamental principle which informs the outlook of the disability rights movement in South Africa and internationally is the right to selfrepresentation. This means that the collective determination of disabled people must be used to inform the strategies of the government.

In recognising this principle, the Government acknowledges the advisory and technical support role of organisations of persons with disabilities and their representatives in the decision-making processes.

2.2 Strengthening diversity and self-advocacy programmes for persons with disabilities (taking into consideration intersectionality issues);

The Irene Declaration made a resolution on self-representation and participation of persons with disabilities. It states:

- 9. Representative organisations of persons with disabilities play a central role in monitoring process with the implementation of the UN Convention on the Rights of Persons with Disabilities and the White Paper on the Rights of Persons with Disabilities;
- 2.3 On Strengthening Self-Representation by Persons with Disabilities it states that:
- 10. Persons with disabilities requiring reasonable accommodation support to represent themselves must have affordable and timeous access to such services and/or technology;

- 11. Representative organisations of persons with disabilities must be strengthened at all levels, and particular attention must be paid to strengthening the organised voice of persons with disabilities which are currently under-represented;
- 12. A resourcing strategy must be developed to enable representative organisations of persons with disabilities to strengthen internal accountability mechanisms, and to participate in advocacy and monitoring programmes;
- 13. Political parties must walk the talk by ensuring that their election lists for public representatives equitably reflect persons with disabilities.

In South Africa, self-representation and participation are gradually being embedded in all decision-making, public consultations, public structures and other environments.

2.4 Self-Representation and Participation from the Perspective of Twin-Track and Intersectional Approach to Disability-Inclusive Development.

The twin-track approach to disability programme was originally based on mainstreaming disability while simultaneously undertaking targeted measures is known as the 'twin-track approach' to advancing disability-inclusive development as illustrated below:



(adapted from DFID, Disability, Policy and Development (2000) 4).

South Africa's Constitution provides for the promotion and advancement of the rights of persons with disabilities, as part of groups who remain marginalised, which also include women, children, youth, the aged, and the LGBTQI+ community, who are usually the victims of multiple, intersecting and aggravated forms of discrimination.

The intersectional approach recognises these multiple factors including, **sex**, **gender identity and sexual orientation or other characteristics for marginalised groups such as persons with disabilities.**¹⁸

Intersectional programming recognizes that multiple social identities such as **gender identity and expression, sexual orientation, disability, race or ethnicity** intersect in a marginalized individual's experience and are affected by the broader existence of privilege and oppression in society.

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Members of excluded and vulnerable groups share common strategies to defend their human rights, as well as to mitigate and prevent human rights abuse. They also develop strategies to address their specific needs and other variations such as age, socio-economic status, or geography that can impact them in different ways.

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http://www.med.monash.edu.au/gendermed/sexandgender.html; http://www.iamsocialjustice.com

A broader **inclusivity approach values the participation of all people**. It assumes that **interventions will not affect all segments of society in the same way**. It requires stakeholders to identify and address the difference between the opportunities and barriers to equality and to design programmes in a way that does not perpetuate inequality.

Inclusive programming works to advance the human rights of Persons with Disabilities, Women and Girls, Lesbian Gay Bisexual Transgender and Intersex persons and other marginalized groups. Such programming **supports the unique experiences and multiple social identities of individuals** that impact their exclusion from society and takes an intersectional approach to program design and response. Advocacy can include:

- Establishing gender-inclusive intra-office procedures
- Encouraging organisations to adopt policies related to gender, sexual orientation and non-discrimination
- Ensure counselling and health care staff understand needs of all communities.

2.5 Self-Representation: Disability and Gender Mainstreaming

2.5.1 Why Gender and Disability

Self-Representation should also be addressed when addressing gender and disability.

Gender describes the characteristics that a society or culture delineates as masculine or feminine. Drawing from the gender mainstreaming experience, Albert and Miller (2005:16) note that at the outset, the emphasis placed on mainstreaming equality at the organisational level (e.g. organisational structures, procedures and culture) emerges from a long struggle to integrate equality issues at the programmatic level (e.g. country strategy papers, sector strategies, Poverty Reduction Strategy Papers, Sector-wide Approaches to Programming, and technical assistance).

Findings from Derbyshire's evaluation of mainstreaming gender equality (Albert & Miller, 2005:16) point to the **'evaporation'** of policy commitments at the organisational-level. Such evaporation of policy, notes Albert and Miller (2005:16) in the planning and implementation processes was a result of inadequate management procedures and the lack of commitment, understanding and skills among staff. This observation has relevancy to disability mainstreaming.

There is now greater awareness that effective management and implementation of initiatives to promote equality at the programmatic level requires actions to develop staff commitment, understanding and skills, as well as actions to promote equality within development organisations themselves. This submission would appear to

be in line with Wood's (2001:466) contention that developing capacity for implementation is about skills development, participation, communication, transparency, and above all, sustainability (Albert & Miller, 2005:16

Women with disabilities are particularly disadvantaged due to the multiple forms of discrimination they experience. For example, disabled girls are the least prioritised in terms of access to school and education. Development activities such as income-generating programmes for women are largely not accessible to women with disabilities and do not take active steps to include disabled women. Furthermore, girls and women who have a disability are more likely to become victims of physical and sexual abuse. For this reason, the gender perspective must be mainstreamed across all programmes.

Conducting a gender analysis is a requirement for all developing projects and activities, and a gender assessment is required for sector-wide strategies. Both these analyses and assessments should look at the roles and potential inequalities between all women and men within a targeted geographic area and should encompass all individuals, including all forms of diversity (e.g. ethnicity, age, religion, race, disability, etc). In practice, however, taking into account how diversity and gender dynamics might vary within these different groups has often been ignored and forgotten. One of the groups that is most frequently excluded from gender analysis- but is present in all ages, levels of society, geographic regions, and ethnic and racial groups- are men, women, and children with disabilities¹⁹.

When working on gender assessments, it is important to ensure that all individuals are being included within the assessment in order to have an accurate view of gender issues within the country. This is especially true of women with disabilities who often face double discrimination based on their gender and disability. There are also several other valid and important reasons why disability should be including the need to ensure that disability inclusive gender perspectives are integrated in policies, legislation, plans, programmes, budgets and activities in all spheres that affect women with disabilities²⁰.

Countries may opt to use the "Six Domains of Gender Analysis" which identifies six general areas that should be included in gender assessments and analyses, including: (1) access to assets, (2) knowledge, beliefs, and perceptions, (3) practices and participation, (4) space and time, (5) legal rights and status, and (6) power.²¹

¹⁹ USAID (2010)

²⁰ AU Draft African Disability Protocol.

²¹ The Gender Domains Framework was originally developed by Deborah Caro and Deborah Rubin

3. OBLIGATIONS OF PERSONS WITH DISABILITIES

3.1 Irene Declaration-A Rights-holders' Commitment

The Irene declaration states that all stakeholders agreed that:

- 14. Rights-holders must be informed about their rights and recourse mechanisms through public education campaigns;
- 15. Representative organisations of persons with disabilities must strengthen its interface with oversight institutions to ensure that these institutions effectively monitor discrimination against persons with disabilities, and that government institutions budget sufficiently and equitably for service delivery to persons with disabilities;
- 16. Duty-bearers must be accountable to rights-holders, and including disability mainstreaming outcomes in the performance management system of heads of departments, will strengthen accountability;
- 17. Every person with a disability, regardless of race, gender, age, severity of impairment or geographical location, have a right to take decisions for themselves, including being provided with supported decision-making services;
- 18. Parents organisations and representative organisations of persons with disabilities must be at the centre of the design, management and implementation of community-based services;
- 19. All children, regardless of severity of impairment and geographical location, can learn and must have equitable access to appropriate early childhood development and education opportunities;

Stakeholders that adopted the Irene declaration made resolutions related to strengthening accountability of duty-bearers and recourse mechanisms for rights-holders by stating that:

- 20. Measures must be taken at all levels to ensure that rights-holders and duty-bearers are aware of the commitments made in the White Paper on the Rights of Persons with Disabilities, the obligations contained in the UN Convention on the Rights of Persons with Disabilities, as well as protection under existing legislation;
- 21. The Department of Public Service and Administration must implement, in consultation with the National School of Government, a disability rights diversity training course for all public servants, including municipal officials;
- 22. Disability organisations must strengthen and formalise cooperation with paralegal agencies and oversight institutions to hold duty-bearers accountable for exclusion, marginalisation and discrimination against persons with disabilities, especially in rural communities;
- 23. Organisations of and for persons with disabilities must be accountable to their respective constituencies and rights-holders.

Through **self-representation and participation**, persons with disabilities will be able **to play their role of representing and defending the needs of persons**

with in all decisions that them. Objectives to achieve priority actions that could form part of self-representation and participation include to:

- a. Promote and create a positive attitude towards persons with disabilities in communities;
- b. Perform the management, monitoring and evaluation of the implementation of inclusive programmes/strategies/ legislation;
- c. Lobby and advocate for inclusion of persons with disabilities at community and national level;
- d. Sensitize and mobilize communities on the priority areas of policy instruments that should be prioritised in line with national development plans.
- e. Fulfil the role of lobbyist and advocate to Government for the implementation of national and international policies to improve the lives of PWDs;
- f. Fulfil the role of technical experts and advisors pertaining to all matters concerning disability;
- g. Promote empowerment of persons with disabilities in order to take control of their own development;
- h. Mobilize constituencies to engage with governments and stakeholders to understand the rights and needs of persons with disabilities;
- i. Promote inclusion of persons with disabilities as required by the CRPD and other international Conventions;
- j. Mobilise resources from Governments, the private sector and development partners to implement complementary activities in implementing the measures outlined in policy instruments and national/disability strategies;
- k. Account to their members, their networks and Governments, the private sector and development partners for funding received and progress made in support of their work.

The disability movement needs to play a key role in the process, and it will be important to negotiate with the government where the entry points are for participation of DPOs/Service Provider Organisations and other civil society allies.

It organises events such as workshops and conferences in which DPOs and civil society organisations (CSOs) participate with the aim of offering open discussions and to exchange information. CSOs' interventions can be strengthened by:

Improving capacity to deliver Community-Based Services to Persons with Disabilities implementing the resolutions of the Irene declaration related to:

- Provincial governments formalising outsourcing of community-based services to disability organisations, including the delivery of family and care-giver empowerment programmes;
- Provincial governments developing and funding integrated and costed community-based disability services packages that prioritises community-based services to remote rural communities;
• A costed strategy to strengthen and develop community-based representative organisations of persons with disabilities, including parent organisations, in particular in deep rural communities.

The participation of persons with disabilities and their representative organisations is critical to the success of any multi-stakeholder effort to advance the implementation of the Africa Disability Protocol (ADP) and other international treaties ratified by each government.

Persons with disabilities and DPOs provide a greater understanding of the actual experience of disability and thus form a basis for informed decisions. Moreover, participation and inclusion are empowering and facilitate active agency in decision making.

In actively consulting with persons with disabilities and their representative organisations, it is important that steps are followed to ensure full and effective participation. It is important to take into account accessibility considerations, to ensure the full participation of all members. Advanced planning by relevant government officials is therefore necessary and important.

Relationship/interaction between governments - Building sustainable partnerships between government and DPOS ('nothing about us without us'; 'leaving no one behind') are essential ingredients in self-representation and participation. Government needs to understand i*ts role vis-à-vis* that of the DPOs. Below is a summary displaying the different roles that are supposed to be played by the two entities.

Demand side: DPOs as rights holders	Supply side: Government as duty bearers	Shared roles between governments and DPOs
Advocacy and influencing	Policy and legislative	Awareness raising
Research and evidence	Systems/ structures/	Knowledge building and capacity development
Partnership building	Partnership building and co- ordination	Partnership in implementation of programmes
Resource mobilisation	Planning and budgeting	Reporting to relevant bodies, nationally, regionally and internationally

Table 2: DPOs' role vis-à-vis that of the Government

Participation in policy	Implementation	
development, planning,	and monitoring	
implementation and	and evaluation	
monitoring and evaluation		

3.2 Obligations of Government, Business and Civil Society

The functions in Table 1 above are typical roles of governments. Policy formulation, based on international/ regional treaties, policies, legislation and national development strategies are key instruments in the mainstreaming and inclusion of the needs of persons with disabilities.

Other roles of government and other duty-bearers include:

- 1. Domestication of the ratified treaties by ensuring that all obligations are covered in law;
- 2. The SA Human Rights Commission must strengthen its capacity to ensure that it does justice to its designation as independent monitoring mechanism for the implementation of the UN Convention on the Rights of Persons with Disabilities;
- 3. Committees in the legislatures must ensure that departmental budgets and performance plans incorporate the policy directives of the White Paper on the Rights of Persons with Disabilities.
- 4. Public finance mechanisms such as conditional grants for infrastructure, transport systems and neighbourhood and city development, provide an opportunity to make neighbourhoods universally accessible for all;

Other roles relate to the government's departmental machinery/clusters. For instance:

- 1. In the field of health, the role of government could be, among others:
 - a. The Department of Health must strengthen undergraduate, in-service and orientation education, awareness and training programmes on the rights of persons with disabilities to health services for, among others, health workers and traditional healers;
 - b. Persons with disabilities and parents of children with disabilities must have access to immediate and relevant information and peer counselling following diagnosis of disability;
 - c. The Department of Health must strengthen inter-governmental relation structures for better inter-sectoral planning, implementation, monitoring and reporting on health access and outcomes for persons with disabilities, and in particular for children with disabilities;

- d. SANAC must conduct a participatory evaluation of the impact of the current National Strategic Plan (NSP) for HIV, STIs and TB on the lives of persons with disabilities, and must ensure that the revised NSP is aligned with the principles and directives of the White Paper on the Rights of Persons with Disabilities;
- e. The Department of Health must ensure that the re-engineering process of primary health care and ideal clinics and the Pillars of the Health Promotion Policy incorporate universal design principles and standards, and that a participatory evaluation is done of existing NHI pilot sites to highlight shortcomings of disability mainstreaming into the services provided on these sites, including access to facilities, and access to communication and information;
- f. The Department of Health must accelerate the finalisation of the new rehabilitation policy, including provisioning of assistive devices and orthotics and prosthetics;
- g. Government must roll out a sustainable on-going disability training programme for all frontline workers, including social workers, educators, nurses, doctors and therapists;
- 2. Provincial and district disability rights forums must be strengthened and focus on removing bottlenecks that hinder access to ECD and compulsory education for, and tracking exclusion of, children with disabilities;
- 3. Other examples for different state actors include the need for:
 - a. The SA Human Rights Commission, as well as the national departments of Health and Social Development, to engage provincial departments on the current process of de-institutionalisation of persons with severe psychosocial, intellectual and/or neurological disabilities to ensure that their rights are being protected and upheld at all times during the process, and that no-one is discharged into the community, their families and/or into other facilities without proper planning, adequate living conditions, rehabilitation and care services available in the community where they will stay;
 - b. The Department of Justice and South African Police Services to expedite the roll-out of Augmentative and Alternative Communication technology and services to strengthen access to justice for persons with severe communication disabilities, and in particular for those living in rural areas;
 - c. The Department of Trade and Industry to expedite the process of ratification and domestication of the Marrakesh Treaty by setting up the Authorised Entities, preparing the systems, affordable playback devices, content development and production guidelines;
 - d. South African Sign Language to become an official language of the Republic of South Africa and the process of tabling an amendment to the Constitution

through the Constitutional Review Committee in Parliament, must be expedited;

- e. Accelerating access to and regulation of services promoting access to information and communication.
- 4. Department of International Relations to conduct an audit of existing bilateral and multilateral international agreements to ensure that persons with disabilities benefit equitably from and participate equally in the programmes of these agreements;
- 5. South Africa to adopt the Africa Disability Protocol and support the development of a SADC Protocol on Persons with Disabilities;
- 6. The African Renaissance and International Development Fund Act must be audited to determine its contribution towards improving the lives of persons with disabilities.
- 7. The National Disability Rights Coordinating Mechanism in Government must establish a panel of entrepreneurs with disabilities and parents of children with disabilities who can provide implement support for the WPRPD;
- 8. All government institutions must ring-fence a budget for participation by and empowerment of young persons with disabilities, and must report annually on the impact of these programmes;
- 9. The National Youth Development Agency must ensure that young persons with disabilities participate in youth dialogues and programmes during National Youth Month;

When implementing policies/legislation, government must follow recommendations from research, baseline studies or statistical data as a basis for activities or interventions of the plan and the identified gaps could be used as the justification for the interventions. In this case, the aim is to facilitate the development of a sector-wide, multi-tier disability mainstreaming plans, with fiscal allocations, to be deliberated and adopted by stakeholders.

Typically, government planners should/must:

- i. Analyse the identified gaps and recommendations;
- ii. Analyse the national development plan in relation to disability;
- iii. Analyse initial plans or inputs from different ministries;
- iv. Hold consultations with working committees and representatives of stakeholders;
- v. Hold focus group sessions with stakeholders;

- vi. Ensure the disability indicators are set for all government departments and ministries;
- vii. Prepare the disability mainstreaming plans with budget;
- viii. Complete a logical framework approach (lfa) matrix, concise implementation plan and budget for each department;
- ix. Make a presentation of the national disability mainstreaming plans to stakeholders and finalise the plan after comments; and
- x. Prepare detailed report on implementation outcomes for different oversight and monitoring structures.

There is increasing focus on the role of 'disability focal points'. There are many arguments for and against this approach. Those who support view focal points as mechanisms that ensure disability mainstreaming. The Irene declaration states that: 'Disability rights units at institutions of higher and further education and training play a pivotal role in providing effective access to campus life and the curriculum for students with disabilities';

However, some argue that focal points are often used as '*dumping grounds*' for all matters related to persons with disabilities (including housing, assistive devices, transport, and others). Below is a typical role played by focal points.

Focal points

The work of focal points can include, among others:

- advising the Head of State/Government, policy makers and programme planners on the development of policies, legislation, programmes and projects with respect to their impact on people with disabilities;
- coordinating the activities of various ministries and departments on human rights and disability;
- coordinating activities on human rights and disability at federal, national, regional, state, provincial and local levels of government;
- revising strategies and policies to ensure that the rights of persons with disabilities are respected;
- drafting, revising or amending relevant legislation;
- raising awareness about the Convention and Optional Protocol within the government;
- ensuring that the Convention and Optional Protocol are translated into local languages and issued in accessible formats;
- establishing an action plan for implementation of the Convention;
- monitoring the implementation of the action plan on human rights and disabilities;
- raising awareness on disability-related issues and the rights of persons with disabilities among the public;
- building capacity within the government on disability-related issues;
- ensuring that persons with disabilities participate in the development of policies and laws that affect them;
- encouraging persons with disabilities to participate in organisations and civil society, and encouraging the creation of organisations of persons with disabilities.

Government's plans for self-representation should include the following sections: Suggested key content list:

- 1. Foreword
- 2. Introduction
- 3. Situation of disability and context of the national programme
- 4. Vision for disability according to the national policy or national strategy for disability
- 5. Mission of the national programme according to the national policy or national strategy on disability
- 6. The national programme: aims, objectives, activities, as informed by the following:
- 7. International, regional and national frameworks;
- 8. The gaps and recommendations of the baseline study;
- Relationship between self-representation and National Development Plan (NDP) including entity budgets;
- 10. Ministerial plans that include self-representation strategies;
- 11. Different roles by stakeholders, including the CSOs.
- 12. Logical Framework for Programme for self-representation

13. Monitoring and evaluation plan, including the following:

- a. Disability targets and indicators pertaining different ministries;
- b. Statistics and disability and self-representation including topics related to cost-benefit, effectiveness, capacity and accountability;
- c. Reporting obligations with the AU and UN;
- d. Budget

The National Disability Rights Coordinating Mechanism in Government provides an opportunity for self-representation.

4. LIMITATIONS AND EXCEPTIONS

4.1 Scope of application

This framework will assist rights holders and duty bearers to plan on inclusion of self-representation within their entities and in line with their core/ancillary businesses. The framework can be used in tiers of government, state-owned enterprises, and the private sector and in civil society organisations.

Institutions promoting democracy, as well other oversight institutions such Parliament and the provincial legislatures, play an important role in **strengthening accountability of duty-bearers and providing recourse for rights-holders including courts (**e.g. equality courts) must use the framework during their work, public hearings and other proceedings/deliberations. Persons with disabilities **are not a homogenous group**, and race, age, gender, severity of impairment, geographical location, sexual orientation and socio-economic status impact on access to services/opportunities and ability to self-represent their needs without assisted decion-making.

The right to self-representation is not negotiable, and requires strong accountable and representative organisations of/for persons with disabilities at all levels of governance, and cognisant of race, gender, age, geographical location and impairment-specific nuances.

4.2 Legal Interpretations of Limitations and Exceptions

Some of the historical human rights instruments fall short of the minimum standards for ensuring the rights of persons with disabilities which are established in the CRPD. For instance, there are still laws that discriminate against persons with psychosocial and mental disabilities.

Some instruments do not include specifically persons with disabilities in antidiscrimination provisions. In addition, people with disabilities have far too often been **excluded by not being mentioned**, a matter of some significance particularly where **other key groups liable or vulnerable** to discrimination are mentioned²².

A notable paradox is the fact that while some instruments establish human rights, their treatment of the subject of disability includes a noticeable dose of the charity model of disability. The charity model anticipates that persons with disabilities have 'needs' as distinct from 'rights'. Again, for example, while 'special measures of protection' cannot be discounted as essential to ensure the rights of persons with disabilities, some rights instruments emphasise protection measures almost to the exclusion of the inherence of rights for disabled persons and their promotion²³.

The language employed in in some human rights policy/strategy instruments tends to fall short of the minimum standards established in the CRPD. For example, reference to 'physically and mentally challenged', thereby employing a euphemism – 'challenged' – which is not appropriate from a human rights approach to disability where a person with disabilities' 'problem' is located in society rather than in the individual.

²² Mute, L. (2012) Concept on the list of issues to guide preparation of a protocol on the rights of persons with disabilities in Africa.

²³ Ibid

Multiple discrimination: The living conditions of persons with disabilities mean that they are often marginalised at multiple levels, including lack of self-representation /participation, gender, race, age, HIV/AIDS and ethnicity. Taking the example of HIV/AIDS, it is important to consider and recognise that HIV/AIDS impacts negatively on disabled persons in all spheres of life. This is exacerbated by the fact that issues of sexuality are not often openly discussed; and that persons with disabilities are more likely to suffer rape and maiming in situations of conflict especially given the assumption that disabled persons are less likely to be infected with HIV.

Interaction between poverty/disability and impact on self-representation:

It is important to address poverty eradication as both a means to prevent disability and to provide effective redress to persons with disabilities. Any meaningful initiatives to address the needs and problems of persons with disabilities must of necessity consider **how to equitably allocate economic resources in order to increase the economic means and capacity** of disabled persons to selfrepresent their needs. It is important to enable persons with disabilities to selfrepresent and have an equal share in the improvements in the living conditions resulting from economic and social development.

Disempowering (cultural/other) practices: Policy measures are required to combat cultural and /or religious practices which disempower or discriminate against persons with disabilities thus reinforcing negative attitudes that make it **difficult for persons with disabilities to self-represent themselves**. For instance, measures to ensure that children with disabilities achieve the fullest possible social integration and individual development should include steps towards the cultural and spiritual development of the child and active participation of parents/guardians. It is necessary to ensure that parents of children with disabilities access information, referrals and counselling.

5. UNJUSTIFIABLE HARDSHIPS

Unjustifiable hardship is legally defined as "an action that requires significant or considerable difficulty or expense."

In some circumstances, it may be unreasonable to provide complete accessibility to a public building, particularly for old existing buildings. Adjustments to a workplace to accommodate a person with disability could also be very onerous. The principle of unjustifiable hardship provides an exception if the cost or difficulties of providing access will place an unjustifiable hardship on a person or organisation. However, before coming to this conclusion, a person or organisation should:

- thoroughly consider how access might be provided or adjustments made
- discuss the issues directly with the person or groups involved
- consult relevant sources of advice.

Unjustifiable hardship is based on an assessment of what is fair and reasonable in the circumstances. If the proposed adjustments are likely to cause hardship, it is up to the person or organisation to show that they are unjustified.

Self-representation is unlikely to cause unjustifiable hardships when there are many choices with regards to accessible venues, translation/interpretations, mobility and other assistive devices and other requirements based on nature of disability.

6. LEGAL PROHIBITIONS

A legal prohibition is a *legal restriction against the use of something or against certain* conduct²⁴.

Certiorari is a formal request to a court challenging a legal decision of an administrative tribunal, judicial office or organization (eg. government) alleging that the decision has been irregular or incomplete or if there has been an error of law. As certiorari seeks to have a decision overturned for want of jurisdiction (*ultra vires*), prohibition seeks to prevent a prospective decision; to stop a lower court or tribunal "*from doing something in excess of its jurisdiction*²⁵".

There are legal provisions that relate to self-representation and participation of persons with disabilities. South African legal instruments that have provision relate to self-representation include:

i. The **Promotion of Equality and Prevention of Unfair Discrimination Act**, 2000 (PEPUDA or the **Equality Act**, **Act** No. 4 of 2000) is a comprehensive South African **anti-discrimination law**. It prohibits **unfair discrimination** by the government and by private organisations and individuals and forbids hate speech and harassment²⁶; among other things, states that "*Special measures to promote equality with regard to race, gender and disability*

28. (1) If it is proved in the prosecution of any offence that unfair discrimination on the grounds of race, gender or disability played a part in the commission of the offence, this must be regarded as an aggravating circumstance for purposes of sentence.

(2) The South African Human Rights Commission must, in its report referred to in section 15 of the Human Rights Commission Act, 1994 (Act No. 54 of 1994), include an assessment on the extent to which unfair discrimination on the grounds of race, gender and disability persists in the Republic, the effects thereof and recommendations on how best to address the problems.

(3) (a) The State, institutions performing public functions and all persons have a duty and responsibility, in particular:

²⁴ Duhaime's Law Dictionary

²⁵ Wade, William, Administrative Law (Oxford: University Press, 2000), page 592

²⁶ Republic of South Africa (2000). Promotion of Equality and Prevention of Unfair Discrimination Act. Act No 4 of 2000. Chapter 5, Section 28.

(i) eliminate discrimination on the grounds of race, gender and disability;

(ii) promote equality in respect of race, gender and disability.

(b) In carrying out the duties and responsibilities referred to in paragraph (a), the State, institutions performing public functions and, where appropriate and relevant, juristic and non-juristic entities, must—

(*i*) audit laws, policies and practices with a view to eliminating all discriminatory aspects there of;

(ii) enact appropriate laws, develop progressive policies and initiate codes of practice in order to eliminate discrimination on the grounds of race, gender and disability;

(iii) adopt viable action plans for the promotion and achievement of equality in respect of race, gender and disability; and

(iv) give priority to the elimination of unfair discrimination and the promotion of equality in respect of race, gender and disability.

Finally, it is possible to enforce the right to self-representation.

End of Chapter One

CHAPTER 2: SELF REPRESENTATION AND RIGHTS OF ACCESS TO SERVICES

2.1 Rights perspective, rights of access and principles of Self-Representation

2.1.1 Problem Statement

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. However, there are **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 state²⁷.

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.

2.1.2 Right of 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.²⁸

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

²⁷ The Presidency, Twenty-review South Africa (1994-2014): Background Paper: Disability

²⁸ The Presidency, Twenty-review South Africa (1994-2014): Background Paper: Disability

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 interventions²⁹.

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

Universal access and design in 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.

The racial discrepancies with regard to access to these core services are well documented (Nkeli, 2008), but embarking on a transformation agenda means that these key government departments have to deal with redress by adopting the principle of improving equity in access across the sectors.

The CRPD has **Article 12 Equal recognition before the law.** Among other provisions, the article states that *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*³⁰.

Article 13 Access to Justice states that:

- 1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
- 2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Table 3 below reflects a few cases that relate to access to justice.

Table 3: Access to justice as demonstrated by four cases³¹

²⁹ Ibid

³⁰ UN CRPD

³¹ Ibid

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.

The right to access cross-cuts along all sectors of government and society. For instance, the provision of education for children and young persons with disabilities requires urgent attention, **starting with access to inclusive early childhoo**d development opportunities. It is, however, important to note that achieving *equity in access to special schools* detracted both communities and government officials from **keeping an eye on equality of outcomes in the educational sector.**

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 delivery³².

Deaf persons' 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 audiovisual broadcasts.

The Preamble to the CRPD states that:

(v) Recognizing the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and

³² The Presidency, Twenty-review South Africa (1994-2014): Background Paper: Disability

communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms³³.

In Article 2: Definitions, the CRPD states that for the purposes of the Convention: "Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, humanreader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

Article 9 on Accessibility states that:

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility³⁴. This article specifies several measures to achieve accessibility.

This articles also obligates State Parties Subject to take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 19 on Living independently and being included in the community states that States Parties to the Convention should recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that persons with disabilities have access to a range of inresidential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Article 20 Personal mobility states that States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- 1. Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- 2. Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost

Other articles that address the **right to access** include:

1. Article 21 Freedom of expression and opinion, and access to information

³³ UN CRPD

³⁴ UN CRPD

- 2. Article 23 Respect for and the family which partly defines effective and appropriate measures: to access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.
- 3. Article 24 Education: States Parties recognize the right of persons with disabilities to education; ensure an inclusive education system at all levels; access to an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live and to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others.
- 4. Article 25 Health: to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation.
- **5. Article 27 Work and employment:** access to a labour market and work environment that is open, inclusive and accessible to persons with disabilities and a labour market/work environment that is open, inclusive and accessible to persons with disabilities.
- 6. Article 28 Adequate standard of living and social protection: to ensure equal access by persons with disabilities to clean water services, appropriate/ affordable services, devices/other assistance for disability-related needs; access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes/poverty reduction programmes; access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care; to public housing programmes; and to retirement benefits and programmes.
- 7. Article 29 Participation in political and public life
- 8. Article 30 Participation in cultural life, recreation, leisure and sport: including cultural materials in accessible formats; television programmes, films, theatre and other cultural activities, in accessible formats; to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance; sporting, recreational and tourism venues; children with disabilities have equal access with other children to participation in play, recreation/leisure/sporting activities, including those activities in the school system; and to services from those involved in the organization of recreational, tourism, leisure and sporting activities.
- **9.** Article 32 International cooperation: Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities; and facilitating cooperation in research/ access to scientific and technical knowledge.

The Africa Disability Protocol also has the following articles, among others, that define measures on the right of access:

- 1. Article 4: Right to Life
- 2. Article 8: Equal Recognition before the Law
- 3. Article 9: Right to Access Justice
- 4. Article 10: Right to Live in the Community
- 5. Article 11: Accessibility

2.1.3 Barriers to Access and Participation

Persons with disabilities experience three main types of interrelated barriers:

- (a) Social (including high cost, lack of disability awareness, and communication difficulties);
- (b) Psychological (such as fear for personal safety); and
- (c) Structural (including infrastructure, operations and information).

A barrier is anything that stops a person with a disability from fully taking part in society because of that disability. Some examples of barriers found in outdoor environments include:

- Curb cuts, ramps and railway crossings that are too steep or not properly maintained, or contain abrupt changes in slope.
- Lack of accessible parking spaces size of spaces, location, number and enforcement of accessible parking spaces.
- Lack of textural changes and colour contrasts for staircases, entrances, ramps and curb cuts.
- Lack of wide clearance on a priority basis near hospitals and clinics, at intersections and transit stops and at public facilities.
- Insufficient number of drop-off/pick-up areas for para-transit users
- Lack of audible traffic signals at key intersections.
- Inadequate lighting that can cause a problem for people with vision loss.
- Confusing signs that prevent people from getting the information they need.
- Physical barriers created by business advertisements or patios on narrow walkways and other public spaces.

Some of the common barriers for people with mobility and agility disabilities include:

- environments inaccessible to people who use wheelchairs or motorized scooters (no curb cuts at intersections or ramps adjacent to stairs);
- steep grades and slopes;
- lack of grab bars, handrails and resting areas inside and outside public facilities;
- soft or unstable surfaces;
- narrow widths of sidewalks and paths due to the placement of street furniture (e.g. benches, and trash receptacles;
- heavy entrance doors; and
- lack of barrier-free public transportation

There are also discriminatory barriers that perpetuate the exclusion and segregation of persons with disabilities. 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 laws, have detracted from progress being made in the achievement of human rights of persons with disabilities in both the private and public sector³⁵.

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, socioeconomic 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 psychosocial disabilities and deaf persons due to the lack of access to sign language and interpreters.

2.1.4 Principles of Self-Representation

The principles of self-representation are paramount in ensuring an adequate standard of living, and goes hand in hand with the concepts of empowerment, participation and independent living.

Recognition of representative organisations requires duty-bearers to put in place systems that regulates self-representation for purposes of consultation during policy and programme development, implementation and monitoring and evaluation (M&E) processes in order to ensure the collective representative voice of persons with disabilities. Consultation constitutes a more structured process of self-representation whereby persons with disabilities are provided with access to policy and programme development processes and can participate in M&E processes on issues affecting their lives. This requires that representative organisations/structures of persons with disabilities who are affected by a specific area of focus, apply for recognition with the relevant institutions for purposes of consultation, and that the outcomes of such consultations are shared with management and governance structures.

Close consultation and participation of persons with disabilities in any planning process that concerns them is a right recognized in the CRPD, as well as one of its key principles. Actions to enhance participation of persons with disabilities and their representative organizations are:

- (a) Identify key actors, at both governmental and civil society level.
- (b) Involve organizations that represent men, women and children with all types of disabilities, including groups representing people with a single impairment, advocacy groups as well as umbrella organizations and those in remote and rural areas, so as to ensure that consultations are representative.
- (c) Facilitate the participation of persons with disabilities who may be marginalized in their own communities, such as women and children with disabilities, persons with mental or intellectual disabilities, persons with disabilities from ethnic minorities, and refugees with disabilities.

³⁵ Ibid

- (d) Provide the support, accommodation and capacity building that may be required to facilitate the participation of persons with all types of disabilities – physical, sensory, intellectual and mental - in consultation and decision-making processes.
- (e) Promote the participation of representative organizations of persons with disabilities in wider civil society consultations.
- (f) Choose venues for consultations that are accessible and easily reached and ensure that relevant information process is made available to persons with disabilities, including in alternative formats and languages.

The principles of self-representation are **'not a one-size-fit-all'**. These principles are based on a variety of factors including the nature of disability and circumstances that require self-representation. Generally, the principles include:

- 1. Self-represented persons are informed about their rights and about the consequences of the options they choose.
- 2. They must not find court procedures complex, confusing, intimidating
- 3. They must have the knowledge or skills to participate actively and effectively in their own litigation
- 4. Equal access to justice for everyone, as well as for the timely and efficient administration of justice

The basic principles self-representation, participation and mainstreaming efforts include the following:

- (a) Responsibility for implementing is system-wide, and rests at the highest levels within agencies;
- (b) Adequate accountability mechanisms for monitoring progress need to be established; which includes both setting up gender-based indicators and gender budgeting;
- (c) Initial identification of issues and problems across all areas of activity should be such that differences and disparities between persons with and without disabilities can be diagnosed;
- (d) Clear political will and allocation of adequate resources for mainstreaming including additional financial and human resources, if necessary — are important for translation of the concept into practice;
- (e) Efforts to broaden the equitable participation of persons with disabilities at all levels of decision-making;
- (f) Mainstreaming does not replace the need for targeted, disability-specific policies and programmes, and positive legislation; nor does it do away with the need for disability units or focal points.

(Source: As described by the Division for the Advancement of Women of the Department of Economic and Social Affairs, and adapted here for disability).

2.1.5 Batho Pele Principles

The Batho Pele ("People First") principles are aligned to the Constitution – know the service you're entitled to. Government officials must follow the "Batho Pele" principles which require public servants to be polite, open and transparent and to deliver good service to the public.

1. Consultation

Citizens should be consulted about the level and quality of the public services they receive and, wherever possible, should be given a choice about the services that are offered. All stakeholders should be consulted on the nature, quantity and quality of services to be provided in order to determine the needs and expectations of the end users. Citizens can be consulted through the following: Customer surveys – Campaigns – Imbizo – Workshops³⁶.

2. Service standards

Citizens should be told what level and quality of public service they will receive so that they are aware of what to expect. Citizens should be told what level and quality of public services they will receive so that they are aware of what to expect. Strategies include: •Service charters •Strategic plans •Booklets with standards •Service level agreements.

3. **Access**

All citizens should have equal access to the services to which they are entitled. Examples: • Decentralized offices (one stop shops, and others) • Extended business hours • Use of Indigenous languages and Sign Language • Service charters displayed • Improved service delivery to physically, socially and culturally disadvantaged persons (including infrastructure) • Signage must be clear and helpful • All frontline staff should wear name tags

4. Courtesy

Citizens should be treated with courtesy and consideration e.g. tools, measurements & systems put in place to effect customer care - customer care units & staff.

5. Information

Citizens should be given full accurate information about the public services they are entitled to receive, e.g. • Braille and functional Sign Language, help desks, brochures, posters, press • Information to be available at service points, in various official languages. • Weekly newsletters from the City Managers • Frontline staff training • Induction training is made compulsory to all new employees.

6. **Openness and transparency**

Citizens should be told how national and provincial departments are run, how much they cost and who is in charge. Examples: Citizens should be told how departments are run, how much they cost and who is in charge • The Citizen should know who the Head of the Unit is. The management must be transparent and open to all staff members, e.g. appointment circulars • Regular staff meetings with Management must be encouraged.

7. Redress

If the promised standard of service is not delivered, citizens should be offered an apology, a full explanation and a speedy and effective remedy; and when complaints are made, citizens should receive a sympathetic, positive

³⁶ Department of Public Service and Administration (DPSA) at <u>http://www.dpsa.gov.za/documents/Abridged%20BP%20programme%20July2014.pdf</u>

response. Establish a mechanism for recording any public dissatisfaction, e.g. toll-free number, suggestion boxes & customer satisfaction questionnaires • Each Unit must have a complaints handling system in place • Staff must be trained to handle complaints fast & efficiently.

8. Value for money

Public services should be provided economically and efficiently in order to give citizens the best possible value for money³⁷. Examples: •the use of expenditure controls, •improved internal controls (e.g. private use of phones, budget reviews) •Costs per unit of services delivered.

2.1.6 Consultation across the value chain

Consultations and public participation processes are important in the policy value chain. **The CRPD's Article 4 on General obligations states that:** States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations³⁸.

The CRPD's **Article 33 on National implementation and monitoring** provides for civil society, in particular persons with disabilities and their representative organizations, to be involved and to participate fully in the monitoring process.

Thus, the principles of consultations and participation in the policy value chain are well established in South Africa law and international treaties the country ratified.

The formal public consultations and participation activities, required by regulations, aim to provide citizens with both access to information and opportunities to participate in the process. The term "public participation" denotes the activities where permitting agencies and permittees encourage public input and feedback, conduct a dialogue with the public, provide access to decision-makers, assimilate public viewpoints and preferences, and demonstrate that those viewpoints and preferences have been considered by the decision-makers³⁹.

"The public" in this case refers not only to private citizens, but also representatives of DPOS, CSOs, labour organizations, public officials; and governmental and other

h.net/content/batho-pele-principles

³⁷ Local Government Action available at <u>http://localgovernmentaction.org.dedi6.cpt3.host-</u>

³⁸ UN CRPD

³⁹ RCRA Public Participation Manual, 1996 Edition.

parties. When one considers "the public" in this broad sense, public participation can mean any stakeholder activity carried out to increase public's ability to understand and influence the policy value chain.

In the best-case scenario, the stakeholders interact well, the lines of communication are strong between all the parties, and accessible information flows to and from stakeholders. This last point is important: **public participation or consultations reflect processes that are based on dialogue.** A vital and successful public participation programme requires a dialogue, not a monologue. In other words, information must flow between all stakeholder groups.

Without an active two-way communications process, no party will benefit from the "feedback loop" that public participation should provide. Feedback loops enable dutybearers to monitor public interest or concerns, adjust public participation activities, and respond quickly and effectively to changing needs. The feedback loop is a useful tool for all stakeholders in the process. Rights holders have valid concerns and can often improve the quality of decisions and policy outcomes.

Public input can help policy makers in the policy making and decision-making processes. There are a number of reasons why DPOs and interest groups should be consulted through public participation and why citizens should make an effort to participate in decision-making. The first, and most obvious reason, is that duty-bearers are required, by law, to conduct public participation activities. The second reason to conduct consultations/public participation with public participation is good governance. Rights-holders, interest groups and any other parties have a right to be heard and to expect government to be open and responsive in line with the Batho Pele princes.

2.2 **Products and Services**

2.2.1 Products and Services

The principles, products and services related to self-representation are closely aligned to the CRPD as follows:

The CRPD is informed by an understanding of equality referred to as "substantive equality" or "equality of results." To promote the equality of persons with disabilities in all areas of life and eliminate discrimination, States are required to: provide reasonable accommodation, which consists of the modifications or adjustments that are necessary and reasonable in a particular case to ensure that a person with a disability is able to exercise a certain right; and take the specific measures that are necessary to advance equality.

These measures include **positive action**, **preferential treatment or quota systems**, **for example**, **to advance the inclusion of persons with disabilities** in areas such as education, the economy, politics and employment.

The CRPD recognizes disability as an evolving concept that "results from the interaction between persons with impairments and attitudinal and

environmental barriers that hinders their full and effective participation in society on an equal basis with others." Furthermore, it does not provide a closed definition of persons with disabilities but clarifies that they include "those who have long term physical, mental, intellectual and sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society with others." This means that national definitions of disability should not only focus on the existence of an impairment resulting from a health situation, but should reflect the role of external barriers and focus on participation.

The openness of the definition implies that States may broaden the range of persons protected to include, for example, persons with short-term disabilities. Thus, self-representation, participation and programming should reflect a flexible approach to persons with disabilities, in recognition that the range of subjects it includes may vary in accordance with socio-economic contexts and cultural environments.

Self-representation products/services shall be aligned to the CRPD's eight fundamental principles: respect for inherent dignity, individual autonomy and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacity of children with disabilities.

The CRPD recognizes accessibility to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, as essential to enabling persons with disabilities to live independently and fully participate in all aspects of life (Article 9).

The CRPD requires States Parties to incorporate disability-sensitive measures into **mainstream service delivery**, and **to provide disability-specific services** (twintrack approach) that are necessary to support the inclusion and participation of persons with disabilities. Article 24 of the CRPD, for example, requires States Parties to develop an inclusive education system at all levels, to provide for reasonable accommodation of the individual's requirements and ensure that persons with disabilities are provided with "effective individualized support measures" to maximize their academic and social development. On similar grounds, access to justice by persons with disabilities, in line with Article 13, requires the **removal of barriers to their participation** through the provision of **procedural and age-appropriate accommodations**.

Products and services shall be provided in order to address the needs of individual self-representatives. For instance:

For Deaf or hard of hearing people:

- Interpreter/intervener services;
- Accessible public telephones (e.g., no volume controls), teletypewriter or teletype (tty's) and other adapted devices (e.g., adaptive media, FM and infrared systems in public facilities);
- Information/instructions written with the use of plain and clear language;
- Emergency bells, sirens and audible/visible signals;

- Avoiding background noise and poor acoustics in indoor environments including poor lighting as this can also be a problem for some people relying on speech reading or sign language;
- Enhanced listening systems;
- Sufficient sensitivity training.

For people who are Blind or visually impaired:

Technology and Adaptive Equipment such as: ⁴⁰ Hardware

- Computers
- Power Mac G3
- Scanners
- Laser Printers

Screen Reader Software

 Jaws for Windows 3.7 - Jaws utilizes an internal software speech synthesizer and a computer's sound card to read aloud information displayed on the computer screen thus enabling equal access electronic information

Low Vision Software

 Zoomtext Xtra - Level 2 - Version 7.0 - ZoomText Xtra is a screen magnification and screen reader software programmes designed specifically for the lowvision computer user. ZoomText Xtra includes DocReader", a tool for reading text from any Windows application. DocReader automatically reads through complete documents, including web pages and email.

Scanning and Reading Software

- Arkenstone Open Book reads, edits and manages scanned images from books, magazines, manuals, mail and other printed documents. OPENBook turns a computer system into a scanning and reading machine, offering blind and vision-impaired individuals access to printed materials.
- WYNN Wizard and Reader WYNN (What You Need Now) is a PC-based software package that helps you read, write, study, and comprehend effectively.

Adaptive Equipment

- Low-vision magnifier
- Height adjustable computer tables and arm supports
- Ergonomic chairs

Other measures could include:

- Sufficient use of contrasting colours, raised letters and characters on most signage;
- Good indoor lighting;
- No background noise which can be a barrier for individuals who are relying primarily on sensory input;
- Lack of textural surfaces in indoor and outdoor environments (e.g., no tactile markers warning pedestrians of potential objects in the path of travel on streets);
- Avoiding protruding objects that overhang the path of travel (e.g., wall-mounted light fixtures);
- Barrier-free streets and street crossings;

⁴⁰ <u>http://www.jmu.edu/humanresources/adadevices.shtml</u>

- Accessible building and room layouts; and
- Availability of public documents in alternative formats (e.g., braille, large print, raised print, diskette, tape or readable colour contrasts).

Some of the common barriers for people with cognitive/language disabilities include:

- lack of access to information and special services and difficulties in problem solving (language impairments can cause difficulty in comprehension and/or expression of written and/or spoken language);
- hi-tech environments that place pressure upon individuals or have high performance expectations that do not allow users to operate at their own comfortable levels;
- overly bright environments that confuse and affect concentration; and
- internal and external environments with signage that is difficult to read or understand.

2.2.2 Standard Operating Procedures

Standard operating procedures, including right of recourse and accountability are normally specified in the Constitution, legislation, policies, strategies and guidelines among others.

When self-representation relates to legal proceedings, procedures include:

1. To promote rights of access:

- Access to justice for those who represent themselves requires that all aspects of the court process be open, transparent, clearly defined, simple, convenient and accommodating.
- The court process should, to the extent possible, be supplemented by processes including case management, alternative dispute resolution (ADR) procedures, and informal settlement conferences presided over by a judicial officer.
- Information, assistance and self-help support, self-represented persons should be made available to self- represented persons through the normal means of information, including pamphlets, telephone and courthouse inquiries, legal clinics and internet searches.
- All self-represented parties should be:
 - i. Informed of the potential consequences and responsibilities of proceeding without a lawyer/advisor;
 - ii. Referred to available sources of representation, including those available from Legal Aid, pro bono assistance, community and other services;
 - iii. Referred to other appropriate sources of information, education, advice and assistance.

2. To promote equal justice

a Judicial officers and court officials should do whatever is possible to provide a fair and impartial process and prevent an unfair disadvantage to self-represented persons.

- b Self-represented persons should not be denied relief on the basis of a minor or easily rectified deficiency in their case. The rights of the other party to the proceedings will also have to be taken into consideration.
- c Where appropriate, a judicial officer should consider engaging in such case management activities as are required to protect the rights and interests of self-represented persons. Such case management should begin as early in the court process as possible and principle of fairness and impartiality should be applied.
- d Depending on the circumstances and nature of the case, the presiding judicial officer may:
 - i. may explain the process;
 - ii. inquire whether both parties understand the process and the procedure;
 - iii. make referrals to agencies able to assist the litigant in the preparation of the case;
 - iv. provide information about the law and evidentiary requirements;
 - v. modify the traditional order of taking evidence; and
 - vi. question witnesses.
- 3. Responsibilities of the participants in the justice system both judicial officers and court officials
 - (a) Judicial officers and court officials should meet the needs of self-represented persons for information, referral, simplicity and assistance.
 - (b) Forms, rules and procedures should be developed which are understandable to and easily accessed by self-represented persons.
 - (c) To the extent possible, court officials should develop packages for selfrepresented persons and standardized court forms.
 - (d) Judicial officers and court officials have no obligation to assist a self-represented person who is disrespectful, frivolous, unreasonable, vexatious, abusive, or making no reasonable effort to prepare their own case. However the courts do have tools available for dealing with witnesses/parties whose behaviour in court is not appropriate (contempt of court) or punitive costs orders because of a person's litigation tactics and downright abuse of court process.

When dealing with self-representation, it is essential to make all reasonable efforts to ensure that all segments of the population (with disabilities) have an equal opportunity to participate and have equal access to information in the process. These efforts may include, but are not limited to:

- a. **Providing interpreters, if needed, for public meetings**. Communicating with the community in its language is essential for the two-way information flow required to ensure the public an equitable voice in public participation activities.
- b. **Providing multilingual fact sheets and other information**. Making sure that the materials presented to the public are written clearly in the community's primary language.
- c. Tailoring self-representation and participation programme to the specific needs of the community. Developing a program that specifically addresses the needs of all persons with disabilities will demonstrate, to rights holders, interest in achieving equity and fostering cooperation.

- d. **Identifying internal/external channels of communication** that the stakeholders rely upon for its information, especially those channels that reach the community in its own language. Examples of these "channels" are a particular radio show or station, a local television station, a non-English newspaper, or even influential religious leaders. By identifying and making use of these valuable communication channels, duty-bearers can be sure that the information being publicised reaches its target audience.
- e. Encouraging the participation of rights-holders and/or formation of advisory groups to serve as the voice of the rights holders and stakeholders. Such groups can provide meaningful participation and empowerment for persons with disabilities.

Making information available to rights-holders and providing for their input can improve public perception in the duty-bearers and lead to greater trust and credibility. Trust and credibility, in turn, can lead to better communication and cooperation and can focus the public debate on issues of, among others, selfrepresentation and participation. Establishing trust should be the cornerstone of public participation activities. As an example, the following is a list of things to remember when establishing the procedural credibility of public representation/ participation:

- 1. Remember the factors that are necessary for establishing trust -consistency, competence, care, and honour.
- 2. Encourage meaningful involvement by rights holders.
- 3. Pay attention to process, including equitable access to services, information and infrastructure.
- 4. Explain the process and eliminate any mistrust.
- 5. Be forthcoming with information and make rights holders to participate from the outset in all stages of the value chain.
- 6. Focus on building trust as well as generating good reliable data.
- 7. Follow up, get back to people, and fulfil your obligations as a duty bearer.
- 8. Make only promises that you can keep.
- 9. Provide information that meets people's needs and in accessible formats.
- 10. Get the facts straight and evidence-based data/statistics relevant to the consultation.
- 11. Coordinate within your organization and manage functions effectively.
- 12. Do not give mixed messages or messages that may cause confusion or display lack of knowledge/experience of disability and human rights.
- 13. Listen to and implement messages from the voices of right holders and other stakeholders.

Procedures for self-representation shall also include the following:

- 1. Definition of the nature/purpose of self-representation
- 2. Applicability of self-representation.
- 3. General accommodation criteria and identifying reasonable accommodation for self-representatives.
- 4. Obligations, roles and duties associated with self-representation for rights holders and duty-bearers.

- Timeframes for key processes including any matters that govern the period of office of self-representatives.
 Capacity provided to self-representatives in order to function optionally.

CHAPTER 3: LEGISLATIVE AND CONSTITUTIONAL OBLIGATIONS FOR SELF-REPRESENTATION

3.1 The Constitution of the Republic of South Africa, 1996

The **Constitution of the Republic of South Africa, 1996**, adopted in 1996, outlaws discrimination on the basis of disability and guarantees the right to equality for persons with disabilities. **The Constitution provides legal imperatives towards an obligation to legislate the right to self-representation.**

Section 9 of the Constitution under the heading "Equality", states:

9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair⁴¹.

The inclusion of disability in the nondiscrimination 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).

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).

The Constitution provides for several independent commissions that monitor developments in their respective purviews. These include:

- 4. The Human Rights Commission
- 5. The Commission for Gender Equality
- 6. The Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities

⁴¹ The Constitution of the Republic of South Africa, 1996, (section 9)

- 7. The Pan South African Language Board
- 8. The Independent Broadcasting Authority.

The 'Public Protector' (resembling the ombudsman in other democratic states) is empowered to investigate 'impropriety or prejudice' in any sphere of government, and to take appropriate remedial action.¹⁵

3.2 Related Case Law

- a. In the North Gauteng High Court: CS1 NO: 57331.2011 related to the process to interview and/or appoint suitable short-listed candidate(s) as Magistrates in respect of the +- 51 posts. The judgement inter alia was that:
 - i. [1] criteria used by the 3rd Respondent in short listing candidates for posts as entry level Magistrates and the application thereof at the following places: Mitchels Plain, East London. Stellenbosch, Strand. Benoni, Pretoria North, Johannesburg, Germiston, and Krugersdorp was unfairly discriminatory in that the applicant's (complainant) gender and/or disability was not appropriately considered when the short-listing was done by the 3rd Respondent.
 - ii. [2] The respondents are directed to reconsider the short-listing of the candidates shortlisted in respect of the aforesaid twenty-three (23) posts mentioned in the 11 places, in order 2 above, and to reconsider the application of the applicant in respect of the aforesaid posts fairly having regard to her gender disability and other relevant factors. Respondents should specifically and seriously have regard to the provisions of section 174 and section 9 of the Constitution of the Republic of South Africa Act 108 of 1996 and the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 together with the protocols signed by the Government of the Republic of South Africa dealing with promoting the position of disabled people.

b. In H v Fetal Assessment Centre [2014] ZACC 34"

Section 28(2) of the Constitution — child's best interests must be considered in determining whether to allow the child to claim compensation for a life with disability in "wrongful life" cases

Section 39(1) of the Constitution — may consider foreign law in interpreting the Bill of Rights Section 39(2) of the Constitution — development of the common law — High Court incorrectly dismissed claim on the basis of the exception.

Complex factual and legal considerations — inappropriate to make a final determination on the viability of the child's claim on the record — High Court must make the determination after considering the elements of the law of delict.

c. In De Vos N.O. and Others v Minister of Justice and Constitutional Development and Others [2015] ZACC 21

Criminal Procedure Act 51 of 1977 - section 77(6)(a)(i) - capacity of accused to understand proceedings - constitutionally invalid to the extent that it mandates the imprisonment of an adult accused person - and to the extent that it mandates the hospitalisation or imprisonment of children

Criminal Procedure Act 51 of 1977 - section 77(6)(a)(ii) - capacity of accused to understand proceedings - constitutionally invalid - to the extent that it mandates the institutionalisation of accused

- **d.** In Khoza and Others v Minister of Social Development and Others (2003) social welfare grants provided to South African citizens must also be provided to non-citizen permanent residents; to do otherwise is unfair discrimination.
- e. In National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others (1998) the criminalisation of male same-sex sexual relations is unfair discrimination on the grounds of gender and sexual orientation.
- f. In National Coalition for Gay and Lesbian Equality and Others v Minister of Home Affairs and Others (1999) — an immigration law which provides benefits to married couples discriminates on the basis of sexual orientation and must be extended to provide the same benefits to same-sex life partners.
- **g.** In Minister of Home Affairs and Another v Fourie and Another (2005) the denial of marriage to same-sex couples is unfair discrimination on the basis of sexual orientation.

3.3 Self-Representation in South Africa Courts

A party is permitted to represent him/herself in any court in a matter where he/she is a party to a matter. However, this usually not advisable to do so unless you are familiar with the court processes. If you do intend to act for yourself, it is important that you notify the opposing attorney and the registrar of the High Court, in writing that you plan to represent yourself and that you wish to oppose the matter. If finances are the reason for not having legal representation, a person could apply for legal aid from organisations such as Legal Aid South Africa (www.legal-aid.co.za) or Probono.Org (http://www.probono-org.org/)⁴².

It is a fundamental principle that the accused should be allowed to present his case in court in an effective manner. This will enable him/her to establish the truth about

⁴² Ottis, M. at <u>https://www.justanswer.com/law/expert-mikeotis/</u>

his/her guilt or innocence⁴³. The right to present one's case applies to all aspects of court proceedings where the court makes a factual finding. This right is an expression of the *audi alteram partem* principle and part and parcel of the right to a fair trial⁴⁴.

The notion of a fair and adversarial hearing requires that the accused be given an adequate opportunity not only to challenge and question witnesses against him, but also to present his own witnesses in order to establish an effective defence.

The right to present one's case is also subject to the principle of *"equality of arms"*. The principle of *"equality of arms"* is the guarantee that both sides will be given the same procedural opportunities to prove their cases⁴⁵. Therefore, the court cannot act in a way which gives the prosecution an advantage over the defence⁴⁶. (<u>http://uir.unisa.ac.za/bitstream/handle/10500/1840/10chapter10.pdf</u>)

In order for an accused to present his case effectively, he must, inter alia, have access to statements of state witnesses so that he can adduce and challenge evidence effectively⁴⁷. Thus, this right is also closely related to the right to be prepared for one's trial.

The right to present one's case is also linked to the other rights mentioned in section 35 of the Constitution⁴⁸. The right to present one's case contains a number of subrights, which are directly related to the main right. These sub-rights appear in the trial phase of the criminal process. They comprise rights such as, **the right to crossexamine witnesses, the right to address the court on evidence to be adduced,**

⁴³ It is noteworthy that no onus rests on the accused to convince the court of the truth of any explanation he gives. If he gives an explanation, even if the explanation is improbable, the court is not entitled to convict unless it is satisfied, not only that the explanation is improbable, but that beyond any reasonable doubt it is false. As per Watermeyer AJ (as he then was) in Rex v Difford 1937 AD 370 at 373.

⁴⁴ The 'audi alteram partem" principle literally means 'hear the other side". This means that no ruling of any importance, either on the merits or on procedural points, should be made without giving both parties the opportunity of expressing their views. See S v Suliman supra at 385. The rules of natural justice come into play here. The 'audi alteram partem" principle is followed in judicial proceedings in a number of countries throughout the world, along with the rights such as legal representation, the right to argument and cross-examination, and the leading of evidence.

⁴⁵ See art 14(1) of the ICCPR, which provides that all persons shall be equal before the courts and tribunals. Also see s 9(1) of the 1996 Constitution which provides that: Everyone is equal before the law and has the right to equal protection and benefit of the law". The right of all persons to be equal before the courts, requires that the prosecution and defence be treated equally in a criminal trial.
⁴⁶ In Robinson v Jamaica, supra at 223/1987 at 241, the HRC considered a case where the accused's request for adjournment in a murder trial in order to arrange for legal representation, was denied by the trial court. The Committee found that the refusal raised issues of fairness and violated art 14(1) because of the inequality of arms" between the parties. Also see Weissbrodt (2001) op cit 130.

⁴⁷ See Shabalala v Attorney-General, Transvaal supra at 1593.

⁴⁸ To illustrate this, the right is linked to the following rights such as, the right to present one's case via one's legal representative in terms of s 35(3)(f); the right to remain silent and thus to present one's case in a passive manner in terms of s 35(3)(h); and the right to present one's case in a language that you understand in terms of s 35(3)(k).

the right to give and adduce evidence, the right to address the court at the conclusion of evidence and the right to address the court on sentence. The right to present one's case effectively is fundamental to an accused's right to a fair trial⁴⁹.

The right to present one's case is fundamental to a fair trial. It is also a fundamental requirement of a fair trial, that there be "*equality of arms*". Therefore, the defence and the prosecution must be on an equal footing. This means that each party must be given a reasonable opportunity to present his case, including his evidence, under conditions that do not place him at a substantial disadvantage is a-vis his opponent⁵⁰.

South Africa follows the *accusatorial system*⁵¹. The interpretation of section 167 of the Constitution by our courts, illustrates that the accusatorial system is firmly entrenched in our law. In the accusatorial system, the right to direct confrontation is regarded as one of the essential ingredients in a fair trial⁵²

Access to justice through the Constitutional Court is demonstrated in the four cases in Table 4, 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 the rights of persons

⁴⁹ (<u>http://uir.unisa.ac.za/bitstream/handle/10500/1840/10chapter10.pdf</u>)

⁵⁰ Thus, the parties must have the opportunity to have knowledge of and comment on all evidence adduced or observations filed. See, inter alia, Dombo Deheer BV v The Netherlands (1993) 18 EHRR 213.

⁵¹ The accusatorial system implies that the presiding officer plays a passive role during the trial. He relies on information placed before him by the parties. Please refer to chapter 1, subsection 1.2.2.1 for a detailed discussion about the accusatorial system.

⁵² Many countries such as Botswana, United States and Mexico provide for direct confrontation in their constitutions.

with disabilities are impossible without appropriate environmental universal design and/or redesign.

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		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.

Table 4: Access to justice as demonstrated by four cases

3.4 The Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA)

These included the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA), passed in 2000, which gives effect to the equality clause in the Bill of Rights, and defines 'discrimination' as "any act or omission, including a policy, law, rule, practice, condition or situation which directly or indirectly (a) poses burdens, obligations or disadvantage on; or (b) withholds benefits, opportunities or advantages from any person on one or more of the prohibited grounds." 'Equality' according to the definition of the Act includes equality in terms of outcomes.

This legislation is especially important in recognising the way in which discrimination is manifest in our society and, most importantly, the need to put in place concrete mechanisms to address discrimination and promote equality. Disabled People South Africa (DPSA) explains:

"[The Act] recognises the existence of systemic discrimination and inequalities, particularly in respect of race, gender and disability in all spheres of life as a result of past and present unfair discrimination, as well as the need to take measures at all levels to eliminate such discrimination and inequalities."⁶⁹

The Act deals with prevention, prohibition and elimination of unfair discrimination, hate speech and harassment, and states that neither the state nor any person may unfairly discriminate against any person on the ground of disability, including:

- (a) denying or removing from any person who has a disability any supporting or enabling facility necessary for their functioning in society
- (b) contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility
- (c) failing to eliminate obstacles that unfairly limit or restrict those with disabilities from enjoying equal opportunities, or failing to take steps to reasonably accommodate their needs.

Under the Act, the South African Human Rights Commission and other relevant constitutional institutions may, in addition to any other obligation, in terms of the Constitution or any law, request any other component falling within the definition of the state or any person to supply information on any measures relating to the achievement of equality including, where appropriate, on legislative and executive action and compliance with legislation, codes of practice and programmes⁵³.

In addition to the powers and functions of the constitutional legal structures, these institutions are also competent to:⁵⁴

- a. Assist complainants in instituting proceedings in an equality court particularly complainants who are disadvantaged
- b. Conduct investigations into cases and make recommendations as directed by the court regarding persistent contraventions of this act or cases of unfair discrimination, hate speech or harassment referred to them by an equality court
- c. Request from the department, in the prescribed manner, regular reports regarding the number of cases and the nature and outcome thereof.

Special measures to promote equality with regard to race, gender and disability provide that:

- a. If it is proved in the prosecution of any offence that unfair discrimination on the grounds of race, gender or disability played a part in the commission of the offence, this must be regarded as an aggravating circumstance for purposes of sentence.
- b. The South African Human Rights Commission must, in its report referred to in section 15 of the Human Rights Commission Act, 1994 (Act No. 54 of 1994), includes an assessment on the extent to which unfair discrimination on the grounds

⁵³ Dube K. (2005) '*The role and effectiveness of disability legislation in South Africa*' 54 Government of South Africa

⁽²⁰⁰⁰b)

of race, gender and disability persists in the Republic, the effects thereof and recommendations on how best to address the problems.

c. The state, institutions performing public functions and all persons have a duty and responsibility, in particular to eliminate discrimination on the grounds of race, gender and disability; and promote equality in respect of race, gender and disability.

3.5 Labour Relations Act 1998

The Labour Relations Act 1998 provides for the regulation of unfair treatment in the workplace via a provision on unfair labour practices. The provision in the previous act was very broadly defined. Consequently, courts had wide discretion to decide which treatment constituted an unfair labour practice. The new Act has moved away from broad definitions of unfair labour practices and instead, specifically lists the kinds of treatment that will be regarded as 'unfair'. The Act defines four kinds of such treatment. Most applicable to persons with disabilities are stipulations on unfair discrimination.

3.6 The Employment Equity Act, No. 55 of 1998

The Employment Equity Act, No. 55 of 1998, is based on section 9(3) of the Constitution Act, No.108 of 1996. According to the Constitution:



The **Employment Equity Act No. 55 of 1998** is aimed at achieving equity in the workplace by--

- a. promoting equal opportunity and fair treatment in employment through the elimination of unfair discrimination; and
- b. implementing affirmative action measures to redress the disadvantages in employment experienced by designated groups, in order to ensure their equitable representation in all occupational categories and levels in the workforce. ⁵⁵

⁵⁵ Employment Equity Act No. 55 of 1998

It defines "people with disabilities" as people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment.⁵⁶

Facts about reasonable accommodation:

- 1. The obligation to make reasonable accommodation may arise when an applicant or employee voluntarily discloses a disability related accommodation need or when such a need is reasonably self-evident to the employer.
- 2. Employers must also accommodate employees when work or the work environment changes or impairment varies which affects the employee's ability to perform the essential functions of the job
- 3. The employer should consult the employee and, where reasonable and practical, technical experts to establish appropriate mechanisms to accommodate the employee.
- 4. The particular accommodation will depend on the individual, the degree and nature of impairment and its effect on the person, as well as on the job and the working environment.
- 5. Reasonable accommodation may be temporary or permanent, depending on the nature and extent of the disability.

A key point mentioned in the Code and the Act is that an employer may not -

- a. Employ people with disabilities or.
- b. Retain employees who become disabled, on less favourable terms and conditions than employees doing the same **work**, for **reasons** connected with the disability.

NOTE----No person may harass an employee on the ground of disability. Such harassment may include teasing, ridicule and offensive remarks. Any alleged harassment should be handled by the employer in terms of the guidelines contained in the Code of Good Practice on the Handling of Sexual Harassment Cases published in terms of the Labour Relations Act, 1995. ⁵⁶ ibid
The Act prohibits:

- 1. **Discrimination** on the basis of disability
- 2. Medical testing, unless-
 - a. legislation permits or requires the testing; or
 - b. it is justifiable in the light of medical facts, employment conditions, social policy, the fair distribution of employee benefits or the inherent requirements of a iob.

Thus, the Employment Equity Act, No. 55 of 1998 protects people with disabilities against unfair discrimination in the workplace and directs employers to implement affirmative action measures to redress discrimination.

The Act is supported by the **Code of Good Practice on the Employment of People with Disabilities** which is a guide for employers and employees on promoting equal opportunities and fair treatment for people with disabilities as required by the Employment Equity Act (the Act). The Code is intended to help employers and employees understand their rights/ obligations, promote certainty and reduce disputes to ensure that people with disabilities can enjoy and exercise their rights at work. The Code also helps create awareness of the contributions people with disabilities can make and to encourage employers to fully use the skills of such persons.

The Code is not an authoritative *summary* of the law, nor does it create additional rights and obligations. Failure to observe the Code does not, by itself, render a person liable in any proceedings. Nevertheless, when the courts and tribunals interpret and apply the Employment Equity Act, they must consider it.

The Code states that employers should adopt the most cost-effective means that is consistent with effectively removing the barriers to perform the job, and to enjoy equal access to the benefits and opportunities of employment. Reasonable accommodation requirement applies to applicants and employees with disabilities who are suitably qualified for the job and may be required -

- i. During the recruitment and selection processes;
- ii. In the working environment;
- iii. In the way work is usually done, evaluated and rewarded; and
- iv. In the benefits and privileges of employment.

Schedule 8 of Labour Relations Act: Code of Good Practice: Dismissal

[Schedule 8 amended by s. 57 of Act No. 42 of 1996 and by s. 56 of Act No. 12 of 2002] provides several cases where employment may be terminated. Section **10 deals**

with Incapacity: III health and injury—(1) states that incapacity on the grounds of ill health or injury may be temporary or permanent.

If an employee is temporarily unable to work in these circumstances, the employer should investigate the extent of the incapacity or the injury. If the employee is likely to be absent for a time that is unreasonably long in the circumstances, the employer should investigate all the possible alternatives short of dismissal.

When alternatives are considered, relevant factors might include the nature of the job, the period of absence, the seriousness of the illness or injury and the possibility of securing a temporary replacement for the ill or injured employee.

In cases of permanent incapacity, the employer should ascertain the possibility of securing alternative employment, or adapting the duties or work circumstances of the employee to accommodate the employee's disability. In the process of the investigation the employee should be allowed the opportunity to state a case in response and to be assisted by a trade union representative or fellow employee

The degree of incapacity is relevant to the fairness of any dismissal. The cause of the incapacity may also be relevant. In the case of certain kinds of incapacity, for example alcoholism or drug abuse, counselling and rehabilitation may be appropriate steps for an employer to consider.

Particular consideration should be given to employees who are injured at work or who are incapacitated by work-related illness. The courts have indicated that the duty on the employer to accommodate the incapacity of the employee is more operous in these circumstances

The Technical Assistance Guidelines on the Employment of People with Disabilities (TAG) is intended to complement the Code published in August 2002 to assist with the practical implementation of aspects of the Act relating to the employment of people with disabilities in the workplace. It builds on the Code to set out practical guidelines and examples for employers, employees and trade unions on how to promote equality, diversity and fair treatment in employment through the elimination of unfair discrimination.

The TAG aims to assist employers by helping them to understand:

- Their obligation to implement non-discrimination and affirmative action measures in respect of people with disabilities in the workplace
- Their right to generate economically viable enterprises and/or organisations which effectively provide services and products without discriminating against people with disabilities
- The opportunities that are afforded to them and their enterprises/organisations through the employment of people with disabilities

• Practical ways to move forward that are relevant to their business and that ensure the application of non-discrimination and affirmative action measures for potential and existing employees with disabilities.

The TAG aims to assist people with disabilities by helping them to understand:

- Their right not to be discriminated against in all aspects of employment
- The affirmative action measures to which they may be entitled to through the provisions of the Act
- Their obligation in participating as an informed partner with the employer in the process of employment
- Their right to the provision of reasonable accommodation if required
- Opportunities that exist to prepare for entering and advancing in the workplace
- Practical ways to move forward in preparing for and accessing employment opportunities that may exist.

A case study:

According to Xolani Matyolo, Perrott, Van Niekerk & Woodhouse, in the case between National Education Health and Allied Workers Union ("NEHAWU") on behalf of Lucas and the Department of Health (Western Cape [2004] 25 ILJ 2091 (BCA), the Applicant (employee) had been employed as a general worker in the nursing department of the hospital operated by the Department of Health. After being injured on duty:

- She could no longer be able to bend or lift heavy objects
- Was transferred to the clerical department while she was being assessed.
- Did not cope well there the other employees were unhappy that her work output was low and that she received special treatment.⁵⁷

The employee's application for a more senior position was unsuccessful and the employer applied for her discharge for incapacity in terms of the Public Service Act 1994 but the department required that she be assessed by a specialist and by an occupational therapist.

She was "advised" by her union and refused to be seen by the occupational therapist. Subsequent thereto her employment was terminated for incapacity due to ill health or injury. The Department's code incorporated the Labour Relations Act Code of Good Practice and the employer purported to have complied with the terms of items 10 and 11 thereof.

⁵⁷ Management Of Incapacity Due To III Health: By Xolani Matyolo, Perrott, Van Niekerk & Woodhouse Inc. The full edition of this newsletter may be read at <u>www.elaw.co.za</u> or <u>www.caselaw.co.za</u>

Arbitrator's Findings-----

In determining the fairness of the dismissal the arbitrator noted that the Code of Good Practice in the Employment Equity Act 55 of 1998 was far broader than the Labour Relations Act Code in respect of impairments that amounted to a disability, in that, where impairment amounted to a disability under the Employment Equity Act the employee was entitled to reasonable accommodation.

The arbitrator adopted a purposive approach that the general objective of the statutory arrangements in both the LRA and the Employment Equity Act was to promote procedural and substantive fairness in relation to people with disabilities and to encourage employers to keep people with disabilities in employment if there is good reason to be accommodated. The arbitrator was of the view that the general concept of fairness required an employer to consider whether a particular employee was a person with disabilities under the Employment Equities Act in determining whether there was a sufficient, valid and fair reason to terminate employment. The arbitrator's view was that even in circumstances where the employee had not specifically sought special treatment with reference to the Employment Equity Act and claimed the status of the person with a disability, the above ought to be taken into consideration.

The Arbitrator made a point that disability status is not to be considered only as a weapon to claim special treatment under the affirmative action provisions in chapter 2 of the EEA but that it should also be considered as a shield to protect the person who has a disability from being dismissed from employment for a reason related to that disability.

In this case it was common cause that the employee lived with incapacity on the grounds of ill health or injury within the meaning of item 10 of the Labour Relations Code. After considering the evidence the arbitrator however found that she also fell within the definition of people with disabilities as defined in the Employment Equity Act. On perusal of the evidence it was found that the employer had attempted to accommodate the employee's disability in terms of Section 10 in terms of the Labour Relations Act rather than as an employee with a disability in terms of the Employment Equity Act. The arbitrator considered which procedure would have produced a substantively fairer outcome for the Applicant and concluded had the parties followed the Employment Equity Act Code and the Technical Assistance Guidelines on the employment of people with disabilities at an early stage they all would have informed themselves, worked together and identified possible accommodation.

Having considered the extent of the employer's duty to make reasonable accommodation for the employee, the arbitrator found insufficient evidence that the employer had considered any reasonable accommodation in relation to this rule or the nursing department but all in relation to a clerical job for which she was in any event not qualified. What this means is that more than only looking at alternatives, the employer must also try and "create" a suitable role for the ill employee. What this award raises is that compliance with the Labour Relations Act Code may not be sufficient in instances where ill health leads to disability. The LRA Code requires employers to look for suitable alternatives adapt the employee's current role where possible to accommodate the employee's circumstances. (Xolani Matyolo, Perrott, Van Niekerk & Woodhouse)

Chapter 5 of the TAG provides detailed analysis of reasonable accommodation, offering examples and situations that may require reasonable accommodation for different disabilities. The Chapter also provides:

- i. Criteria for reasonable accommodation
- ii. Application of principles for applicants and employees
- iii. When an employer is obliged to provide reasonable accommodation
- iv. Reasonable accommodation obligation when changes to work, environment or the impairment occur
- v. Consultation with the employee/applicant with a disability and use of technical experts
- vi. Conditions that may affect accommodation
- vii. Reasonable accommodation may be temporary or permanent, depending on the nature and extent of the disability
- viii. Representative list of examples of reasonable accommodation⁵⁸

The TAG also provides guidance on:

- Evaluating performance and reasonable accommodation
- Employers are not obliged to provide reasonable accommodation if it creates an unjustifiable hardship
- Defining unjustifiable hardship
- Unjustifiable hardship cannot be generalised to other employers or to the future
- Frequently asked questions about reasonable accommodation
- Examples where reasonable and unjustifiable criteria might not be objectively determined
 - Best practice Corporate level reasonable accommodation "Hire the passion and train the skill"
 - Best practice for using the Supported Employment Model-Intellectual and other disabilities
- Guidelines for employers
- Guidelines for people with disabilities

3.7 Social Assistance Act No 59 1992

The Social Assistance Act 1992 provides for the rendering of social assistance to individuals, national councils and welfare organisations. The Act was amended in 1994 to further regulate the making of grants and financial awards to certain people and bodies. The Welfare Laws Amendment Act 1997 was amended the Social Assistance Act 1992 in order to:

- Provide for uniformity of, equality of access to, and effective regulation of, social assistance throughout South Africa
- Introduce the child-support grant
- Do away with capitation grants

⁵⁸ Department of Labour: 'The Technical Assistance Guidelines on the Employment of People with Disabilities (TAG)'

- Abolish maintenance grants subject to the phasing out of existing maintenance grants over a period not exceeding three years
- Provide for the delegation of certain powers
- Extend the application of the provisions of the Act to all areas in the Republic.

3.8 The Skills Development Act

One of the purposes of the Skills Development Act is to improve the employment prospects of persons previously disadvantaged by unfair discrimination, and to redress those disadvantages through training and education. In this regard, people with disabilities in particular, among other disadvantaged groups, will be targeted. The Act offers persons with disabilities various forms of assistance, namely:

- 1. A more efficient and effective departmental employment service is offered, capable of informing disabled persons of the various support measures that are available. Expansion of the quality and reach of these services is planned.
- 2. An expanded number and range of learnerships (courses and skills training), geared to meet the needs of community development as well as industry, are planned. Special measures will be in place to ensure that the most vulnerable have access to these opportunities. Some of these learnerships will be designed to help persons with disabilities find work in the formal sector. Others will aim to empower persons with disabilities to become self-employed and self-sufficient. A network of support measures will be established to address the needs of persons with disabilities after they have qualified, to give them a better chance to attain employment.
- **3.** By bringing learning and working opportunities closer to social and economic development needs, the divide between those with work and those without work will diminish. Everyone will have his or her skills recognised via the National Qualifications Framework and hence will be able to sell his or her skills and services in the same market place. People who are able to earn their own income will enjoy the self-respect that such independence brings as well as the sense of achievement that signifies true empowerment.

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.

The **Sectoral Education and Training Authorities (SETAs)** were established in terms of the Skills Development Act, Act 97 of 1998. The 21 SETAs are expected to direct and facilitate the delivery of sector-specific skills interventions that help achieve the goals of National Skills Development Strategy and address employer demand for skilled labour (RSA CRPD Report, 2012).

The National Skills Development Strategy III, released in 2012, acknowledges that previous programmes have failed to achieve equal access for people with disabilities, despite the 4% target that had been set, and re-commits to "significantly open up opportunities for skills training for people experiencing barriers to employment caused by various forms of physical and intellectual disability."

3.9 The National Development Plan (NDP)

The NDP states that:

'Disability must be integrated into all facets of planning, recognising that there is no one-size-fits-all approach. In line with the priorities of the plan, people with disabilities must have enhanced access to quality education and employment. Efforts to ensure relevant and accessible skills development programmes for people with disabilities, coupled with equal opportunities for their productive and gainful employment, must be prioritised' (NDP 2030)

Each chapter of the NDP was analysed and outcomes/results related to disability were set.

3.10 The Preferential Procurement Policy Framework Act, 2000 (Act 5 of 2000)

The Act gives effect to section 217 (3) of the Constitution. Section 2(1) (d) of the PPPFA provides that any organ of state may contract with persons, categories of persons, historically disadvantaged by unfair discrimination on the basis of race, gender or disability.

The Preferential Procurement Policy Framework Act, 2000 (Act 5 of 2000) recognises the economic rights of people with disabilities to engage in entrepreneurial activities that promotes self-reliance and independent living. Measures include access to opportunities within public sector procurement systems, whereby the supply chain management process aims to empower historically disadvantaged communities and a target of 5% access of all preferential procurement has been set aside for entrepreneurs with disabilities.

3.11 The Criminal Law (Sexual Offences and Related Matters) Amendment Act (Act 32 of 2007)

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.

3.12 South African Local Government Association (SALGA) developed the Disability Framework for Local Government (2009–2014)

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

3.13 The South African Schools Act (Act 84 of 1996) (SASA)

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.

3.14 Library for the Blind Act 91 1998

The South African Library for the Blind, declared under Section 1 of the State-aided Institutions Act, 1931 (Act 23 of 1931), continues to exist as a juristic body, notwithstanding the withdrawal of the notice by this Act. The objective of the Library for the Blind is to provide a national library and information service to serve blind readers and other people whose disability does not enable them to read printed materials in South Africa. The functions of the Library for the Blind are to:

- (a) Build up a balanced and appropriate collection of South African and other documents for the use of blind and print-disabled readers
- (b) Record its collections appropriately
- (c) Provide a bibliographic service to those readers
- (d) Provide access to documents nationally and internationally to those readers
- (e) Provide library and information services on a national basis to those readers
- (f) Co-ordinate and preserve the national audio and Braille literary heritage

(g) Produce documents in special media, such as Braille and audio, as required by users.

The functions must be performed solely in respect of documents for the use of or relating to blind and print-disabled readers.

CHAPTER 4: FINANCING SELF-REPRESENATION

4.1 Costing for self-representation

4.1.1 Cost Factors Related to self-representation

The adoption of Sustainable Development Goals (SDGs) resulted in the adoption of the Addis Ababa Action Agenda (AAAA). This Agenda is a global framework for financing development and includes guidelines on **domestic public resources**, **international development cooperation**, **domestic and international private and business finance**, **debt and debt sustainability**, **science**, **technology and innovation and capacity building**.⁵⁹ The Agenda is a useful tool for budgeting and financing of self-representation/participation of persons with disabilities in the development process, service delivery and other benefit schemes.

Self-representation and **participation** go hand-in-hand. To achieve the objectives of self-representation, participation is required and **vice versa**. Both concepts, including mainstreaming strategies, result in **inclusion**.

At an operational level, entities that promote and provide self-representation must plan for all associated costs, such as:

- *a.* Provision of sign language/tactile interpreters, preferably at all events regardless of whether Deaf or deaf blind people are there or not as argued by the users of these services.
- *b.* Providing guides, Braille and related equipment to ensure that the needs of Blind people are addresses.
- c. Personal assistances services
- *d.* Mechanisms/provision of assisted decision-making support services for persons with psychosocial disabilities.
- e. Accessible transport, venues, housing and written/print/electronic and other materials.
- *f.* Other requirements of the diversified disabilities within the population of persons with disabilities.

It is important to facilitate access by persons with disabilities to mobility aids, devices, assistive technologies and all forms of assistance and intermediaries including by making them available at affordable or no cost. Private entities should be encouraged to undertake and promote research, development, and production of new mobility aids, devices and assistive technologies.

⁵⁹ CBM/IDA (2017), TOOLKIT FOR DPOs VOLUNTARY NATIONAL REVIEWS: How to review if the SDGs have been achieved for persons with disabilities in your country! ON PARTICIPATION IN NATIONAL, REGIONAL AND GLOBAL LEVELS.

4.2 What Is the Cost of Exclusion-Analysis of Costs and Benefits

The goal of **self-representation**, **participation** and **mainstreaming** is, partly to achieve **inclusion** in all sectors of the economy and society. These three concepts are at the heart of the philosophy of the disability rights movement and those that support this cause.

The importance of these three concepts can be illustrated by determining the cost of exclusion.

Calculating macroeconomic losses related to disability helps in understanding the scope of disability-associated concerns, and serves as an important basis to calculate the opportunity costs of inactivity, e.g. in the context of a cost–benefit analysis. Nonetheless, in the past, only one empirical study published by the World Bank has tried to estimate losses in Gross Domestic Product (GDP) related to disability (Metts 2000)⁶⁰.

An often-cited calculation of worldwide economic losses related to disability has been provided by Metts (2000) and published by the World Bank. Metts estimates that the total annual value of global GDP lost in relation to disability lies between US\$ 1.37 and US\$ 1.94 trillion⁶¹. The extrapolation technique sets the assumption that GDP losses (in Canada) related to disability are: a positive function of the incidence of exclusion of people with disabilities, because those who are excluded do not contribute; and an inverse function of the general unemployment rate, because a lower unemployment rate infers a higher probability of labour market activity.

The extrapolation carried out by Metts (2000) is an important effort to develop an accumulated figure that summarizes the worldwide economic costs of excluding people with disabilities from the world of work. However, it is clear that the analysis builds on assumptions which are difficult to defend: certainly, the social, cultural, and political structure of Canada does not represent the conditions in the rest of the world; and clearly differences in economic performance between countries cannot be reduced to differences in unemployment rates.

While inclusion, like everything else in society, is not cheap, excluding persons with disabilities has a much higher price. In the long run, leaving disabled people out of development is counterproductive and to do so is to deny them their human rights. Researchers have shown there is a strong financial case to be made for inclusion.

 ⁶⁰, Buckup, Sebastian, The price of exclusion the economic consequences of excluding people with disabilities from the world of work; International Labour Office, Employment Sector, Skills and Employability Department. - Geneva: ILO, 2009 85 p. (Employment working paper; no.43)
⁶¹ Ibid

The World Report on Disability⁶², in 2011, found that persons with disabilities are more likely to be unemployed, and to earn less when employed. Addressing this discrimination in work would have clear economic benefits – increasing production by persons with disabilities, and increasing their spending and reducing over-reliance of social benefits/security measures for a good number of productive persons with disabilities.

Self-representation and participation are essential tools that assist in achieving **economic benefits of disability inclusion** beyond direct access to work. For instance, supporting people with complex disabilities to undertake self-care or to help with household tasks; enabling a child with disability to attend school all have broader benefits in opening up new opportunities and redistributing care burdens, with knock-on economic as well as social impacts.

Pathway 1: Earnings and labour productivity – Exclusion from education may lead to lower employment and earning potential among people with disabilities. Not only does this make individuals and their families more vulnerable to poverty, but it can also limit national economic growth⁶³.

Pathway 2: Non-employment costs and benefits – Increasing access to education can also have positive impacts in areas such as crime, control of population growth, health, citizen participation and gender empowerment, which in turn have financial and social consequences⁶⁴.

Pathway 1: Individual earnings and household income - Exclusion from work/employment of people with disabilities may lead to lower income due to disproportionately high levels of underemployment/unemployment as well as lower pay-scales for performing the same work as individuals without disabilities. In addition to challenges accessing formal employment, people with disabilities also face barriers to informal work and self-employment, due, for instance, to exclusion from micro-credit schemes. Finally, caregivers may forgo work opportunities to assist family members with disabilities.

In South Africa, lost earnings averaged US\$4,798 per adult with severe depression or anxiety disorder per year (about half of GDP per capita) **totalling US\$3.6 billion** when aggregated to the national level⁶⁵.

⁶² World Health Organisation, World Bank (2011)

 ⁶³ Banks, L. M. and Polack, The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from Low and Middle-Income Countries; Tobias Pflanz/CBM
⁶⁴ Ibid

⁶⁵ Banks, L. M. and Polack, The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from Low and Middle-Income Countries; Tobias Pflanz/CBM

Total economic loss due to disabling environment and exclusion from labour market disability is estimated at \$17 818 000⁶⁶. A study was carried out in a selection of ten low and middle-income developing countries, three of which are in Asia (China, Thailand, and Viet Nam), and seven in Africa (Ethiopia, Malawi, Namibia, South Africa, Tanzania, Zambia and Zimbabwe). It came to the conclusion that economic losses related to disability are large and measurable, falling into a band between 3 and 7 per cent of GDP.

Inclusion of people with disabilities in work/employment can lead to greater economic self-sufficiency⁶⁷.

From a human rights and social justice perspective, the widespread exclusion of people with disabilities from society is unequivocally unacceptable. The evidence presented in this report, emphasises that exclusion is also untenable from an economic perspective: not only does exclusion create a significant economic burden for individuals and their families, **but it can also carry substantial costs to societies at large**⁶⁸⁶⁹.

Real costs of exclusion aren't just narrow economic ones: **it is the human costs that matter most**. Equality is a basic human right – an end in itself, not just a means to economic ends. As the Bond disability and development group argues, excluding disabled people from development on any grounds – including cost – is discrimination, and is at odds with human rights treaties such as the UN convention on the rights of persons with disabilities.

4.3 Budget/ Fiscal allocation

It is critical for the government to expressly state how it plans to fund the planned activities. Requisite budget lines should be specifically identified. Often, activities are planned without having been budgeted for, a situation that should be avoided at all costs. Budget considerations should include, but not be limited to:

- activities geared towards implementation;
- training of stakeholders, especially focal points;
- awareness-raising and advocacy work;
- co-ordination;
- monitoring and reporting;
- publication and networking (for instance website, conferences, newsletter);
- research;
- policy reform/harmonisation;
- prioritised ministerial services/infrastructure/activities.

⁶⁶ Ibid

⁶⁷ Ibid

⁶⁸ Ibid

⁶⁹ Extract of a discussions between, among others, Jasmine O'Connor and Hannah Loryman.

- Role of bi-multilateral cooperation. Embedding disability components in development cooperation agreements.
- Other innovative financing mechanisms eg. Multi-sector funds, specific allocation of proceeds from the national lottery and others.

Government's fiscal plans and medium-term expenditure framework must routinely include disability, self-representation/participation by persons with disabilities and **mainstreaming in all sectors of government and society**.

END

CHAPTER 5: INSTITUTIONALISING ARRANGEMENTS FOR COORDINATION OF SELF-REPRESENTATION

5.1 Public Sector

Introduction

The CRPD Article 33 – on national implementation and monitoring provides mechanisms for coordination and coordination mechanism within government to facilitate related action in different sectors and at different levels.

The former Office on the Status of Disabled People (OSDP) in the Presidency was responsible for monitoring the implementation of the INDS in all the government departments, and for facilitating mainstreaming of disability across the public sector as well as in civil society.

Coordination is part of disability considerations be mainstreamed in all planning processes, with a particular focus on (i) equality of outcomes; (ii) universal design; (iii) the removal of barriers; (iv) reasonable accommodation measures and (v) redress, and that a M&E system be put in place which provides an assessment of the impact of the implementation of policies, programmes, services and public sector spend on the lives of persons with disabilities.

Principles informing coordination of self-representation include:

- 1. Persons with disabilities have a right to participate equally with others in any activity and service intended for the general public;
- 2. Principles of universal design and reasonable accommodation provisioning must inform all new and existing legislation, standards, policies, strategies, plans and budgets;
- 3. Targeted programmes and services aimed at redressing and/or to ensure that the diverse needs of persons with disabilities are adequately met must be underpinned by effective planning, adequate allocation of human resources and sufficient financial investment;
- 4. Persons with disabilities must be consulted on selecting appropriate reasonable accommodation measures, assistive technology and personal support; and
- 5. Representative organisations of persons with disabilities (inclusive of parents' organisations) must be consulted throughout the design-planning implementation-monitoring-evaluation-regulation value chain.

Improved coordination of disability rights-based research that articulates national priorities, and which provides sound evidence for future policy and practice decisions, will ultimately lead to improved outcomes for South Africans with disabilities⁷⁰.

M & E requires a significant measure of independent and impartial views, and is therefore best managed and conducted by a multi-disciplinary and multi-stakeholder team of people that account and report to the national disability rights coordinating mechanism on the processes engaged in, and the findings of the process. However,

⁷⁰ WPRPWD

the national disability rights coordinating mechanism remains responsible for leading and ensuring that monitoring and evaluation is implemented.

Collaboration and co-operative M & E by all three spheres of government, the private sector and disabled people's organisations will be facilitated by the national disability rights coordinating mechanism. The provincial and local spheres of government will be supported to set up M & E systems that are aligned and feed into the national system.

The national disability rights coordinating mechanism will establish the necessary coordination structures, mechanisms, processes and systems to fulfil its M&E responsibility.

Article 33 (National implementation and monitoring) of the UNCRPD requires that one or more focal points within government be designated to accelerate implementation of the UNCRPD, and a coordination mechanism must be established within government to facilitate related action in different sectors and at different levels.

Government and coordination machineries must be strengthened at:

- 1. *Institutional level*, responsible for providing strategic direction and technical support in the delivery of equality and elimination of discrimination against persons with disabilities;
- 2. Inter-departmental level (national and provincial), providing strategic direction and technical support in the delivery of equality and elimination of discrimination against persons with disabilities;
- 3. *Inter-provincial level*, responsible for the oversight, management, co-ordination of the implementation of programmes for persons with disabilities in all provinces in order to ensure standards are maintained across provinces;
- 4. *District level*, responsible for coordination of action and sharing of experiences between local municipalities in a district;
- 5. *Local level*, providing support to ward committees to drive local action aimed at promoting and protecting the rights of persons with disabilities; and
- 6. *Government-Civil Society Interface* Provision should be made for full participation of civil society structures at national, provincial and local level, particularly in issuebased working groups.

5.2 Policy Directives: Institutional Arrangements

- 1. Disability rights coordinating mechanisms must be designated and/or appointed in all public institutions;
- 2. Institutional capacity to contribute to the national disability rights agenda across the spectrum of development, statistical and innovation agencies must be strengthened through the development of designated disability-focused programmes and mechanisms;
- 3. Statistics South Africa, as the national statistical body, must establish a Disability Statistics Advisory Group on disability to guide the research, development, testing, validity and analysis of disability question(s) and responses to provide acceptable disability data for inclusion in the national Census, household, labour and other socio-economic surveys. Membership of the Advisory Group must include, among others, national government departments, the South African Local Government

Association, disability organisations, research institutions and institutions of higher education;

- 4. The South African Bureau of Standards must strengthen its universal design capacity in the work of their design institute and standard setting bodies;
- 5. The CSIR must strengthen its capacity to promote universal design in its research, technological innovation as well as industrial and scientific development programmes; and
- 6. The South African Qualifications Authority (SAQA) must strengthen its capacity to promote and coordinate the development of a national universal design qualifications framework.

The role of the public sector can be analysed in line with the tiers of government as detailed in the WPRPWD:

5.3 National Coordination

The President, upon taking office, decides on the macro-organisation of the state, including designation of the national disability rights coordinating mechanism.

Placement must be in accordance with the general system of organisation of functions. The role and functions of the national disability rights coordinating mechanism include:

- (a) Coordination of and technical support for the implementation of the WPRPD;
- (b) Development and coordination of the five-year national disability rights programme of action, aligned with the MTSF;
- (c) Monitoring of and reporting on compliance with the UNCRPD and other international disability-related treaties;
- (d) Coordination and management of government-wide disability rights cooperative governance forums at national level;

5.4 **Provincial Co-ordination**

Premiers, upon taking office, decide on the macro-organisation of provincial administrations, including designation of the provincial disability rights coordinating mechanisms. Placement must be in accordance with the general system of organisation of functions. The role and functions of provincial disability rights coordinating mechanisms include:

- a. Development and coordination of the five-year provincial disability rights programmes of action;
- b. Monitoring of compliance with the UNCRPD and implementation of the WPRPD at provincial, district and local level;
- c. Management of disability rights cooperative governance forums at provincial level;
- d. Coordination of international treaties and national disability rights reporting at provincial level.

5.5 Roles and Functions of Legislatures and the Houses of Traditional Leaders

The National Assembly, the National Council of Provinces, provincial legislatures, municipal councils as well as the national and provincial Houses of Traditional Leaders, through their committee systems, constituency programmes and by involving rights-holders, have important oversight responsibilities in ensuring that every public institution integrates the WPRPD policy Directives into institutional plans, budgets and reports.

The hosting of annual sectoral legislatures (referred to as Disability Rights Parliaments or Councils), is another important mechanism to strengthen accountability by dutybearers to rights-holders. Rights-holders are to strengthen the importance of this function through empowering of their representatives within these Parliaments/Councils.

Traditional leaders, as custodians of traditional customs, play a central role in championing the rights of persons with disabilities in traditional communities, including upholding their rights in proceedings of traditional courts.

5.6 Intra-Institutional Coordination

It is the responsibility of every public institution to put in place structural arrangements to ensure the institution is able to fulfil its obligations as contained in the WPRPD, in accordance with the system of organisation of functions within each institution. This might take the form of designation, appointment of disability rights coordinators/units as well as disability rights intra-departmental committees, which will be responsible for, among others:

- a. Coordinating an institutional analysis and alignment of all legislation, policies, plans, programmes and services of government institutions to ensure effective mainstreaming of disability and implementation of the WPRPD;
- b. Coordinating consultative platforms with civil society;
- c. Conducting quality assurance audits and documenting good practice in disability rights mainstreaming; and
- d. Advising the executive team on progress made and measures that should be taken to accelerate disability rights mainstreaming across all programmes of the institution.

5.7 Roles and Functions of Institutions promoting Democracy

The following State Institutions strengthen constitutional democracy in South Africa, and therefore also play important roles in ensuring that the rights of persons with disabilities are protected and promoted:

- a. The SAHRC;
- b. The Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities;
- c. The Commission for Gender Equality;
- d. The Auditor-General; and
- e. The Electoral Commission

Article 33 (National Implementation and Monitoring) of the UNCRPD requires states parties to establish, among others, an independent monitoring framework to strengthen monitoring of the rights of women, men and children with disabilities at national level by either establishing a new independent monitoring mechanism to conduct the monitoring work, or by strengthening and designating an existing mechanism to enable it to provide the monitoring function required by the UNCRPD. The UNCRPD furthermore anticipates that the independent monitoring mechanism will ensure that civil society, persons with disabilities and their representative organisations participate fully in all aspects of the monitoring processes just as they should be involved in the development and implementation of policies, programmes and legislation to implement the UNCRPD.

Section 13(1)(b) of the South African Human Rights Commission Act, 2013 empowers the SAHRC to "monitor the implementation of, and compliance with, international and regional conventions and treaties, international and regional covenants and international and regional charters relating to the objects of the

Commission", and requires of the SAHRC to prepare and submit reports to the National Assembly pertaining to any of these human rights instruments.

The independent monitoring mechanism is responsible for, among others:

- a. Reporting on human rights matters as it affects persons with disabilities, including submission of reports to the National Assembly;
- b. Contributing to periodic reporting to United Nations treaty bodies and committees, as well as the Africa Commission on Human and People's Rights and its relevant committees;
- c. Making recommendations to Government with regards the harmonisation of national legislation, regulations and practices with international human rights standards;
- d. Participating in national advocacy campaigns promoting the rights of persons with disabilities; and
- e. Considering and processing complaints about human rights violations and discrimination perpetrated against persons with disabilities.

The Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities play a central role in promoting and advancing the cultural rights of persons with disabilities in general, and in particular of the Deaf community.

5.8 Coordination by the Private Sector

The creation of barrier-free environments requires collective and concurrent action by law and policy makers, service providers, regulatory bodies, the private sector as well as organisations of and for persons with disabilities.

The **universal design audits** of all existing infrastructure to establish the degree of compliance with the SABS minimum norms and standards for the use of people with disabilities must be implemented. Disability access of the built environment must include all public and private sector institutions and shared spaces. Quantified and costed plans must be developed to address the outcomes of the audits and the budget must be provided for implementation of the plan by all sectors.

State and private sector should provide incentives and reward systems towards promoting universally designed and accessible built-environments that meet regulated norms and standards. These incentives must be aimed at transforming the attitude of built-environment professionals towards designing barrier-free spaces and facilities.

The promotion of the employment of persons with disabilities in the private sector through appropriate policies and measures, including affirmative action programmes, incentives and other measures shall be prioritised.

Persons with disabilities must self-represent themselves in various structures within the private sector. Such representation shall be in:

- 1. Enforcing compliance with the obligations contained in the UNCRPD as well as Constitution of the Republic of South Africa
- 2. Company Boards
- 3. Company departments responsible for such functions as research/development/ universal design of products/services; procurement structures; employment equity forums; and other company strategies.
- 4. Development of company policies and strategies
- 5. Business chambers and councils
- 6. Business Strategies
- 7. Training and skills development strategies
- 8. Review all programmes targeting children for access to children with disabilities.
- 9. Collaboration and co-operative M & E systems
- 10. Other private sector strategies.

Trade unions and work-place employee structures shall facilitate the self-representation of persons with disabilities.

5.8.1 Roles and Functions of Research and Academic Institutions

Research and academic institutions must ensure that they advance the rights of persons with disabilities in general, and implementation of the WPRPD by mainstreaming disability throughout their research work and academic courses.

5.8.2 Roles and Functions of the Media and Advertising Industry

The media and advertising industry plays a central role in shaping the minds and behaviour of the community.

The vast majority of information about disability in the mass media is extremely negative, with disabling stereotypes which medicalise, patronise, criminalise and dehumanise persons with disabilities. These form the bed-rock on which the attitudes towards, assumptions about and expectations of persons with disabilities are based. They are fundamental to the discrimination and exploitation which disabled people encounter daily, and contribute significantly to their systematic exclusion from mainstream community life.

Media and advertising agencies must therefore transform the industry to provide the kind of information and imagery which acknowledges and explores the complexity of the experience of disability and a disabled identity as well as facilitates the meaningful integration of all persons with disabilities into the mainstream economic and social life of the community.

5.9 Coordination by the Political Sectors

5.9.1 Provision of the CRPD.

The CRPD Article 29 on Participation in political and public life outlines measures that are applicable to self-representation in the political sector. The article provides that:

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

(*i*) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

(b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels⁷¹.

5.9.2 Political rights

All people who have the nationality of a country are called citizens. All citizens have the right to have a say in how their country is run. This means they have political rights. Political rights are for example:

⁷¹ UN CRPD Article 29

a The right to vote in elections

In elections, citizens choose who will run their country, their region or their city. For example, citizens elect their Members of Parliament and have the right to become candidates in elections. A person with a disability should also be able to be a candidate, if he or she fulfils the conditions, as any other citizen.

This means other citizens can vote for persons with disabilities in elections and can become a representative (not necessarily for persons with disabilities only).

Persons with disabilities who are citizens can take part in politics. It means they can have a say in the way their country is run. Permanent citizens have no rights to vote or be voted for but as citizens, persons with disabilities have political rights to vote and be elected to public office. The Convention requires governments to make sure that people with disabilities have the same chances to take part in politics as anyone else.

5.10 Consultative Platforms

5.10.1 National and Provincial Disability Rights Coordinating Mechanisms

The existence of the national and provincial disability rights coordinating mechanisms does not remove responsibility for functional coordination from institutions which have a coordinating function for purposes of government-wide planning, M&E, budgeting and financial oversight, building a capable public administration, regulating the labour market and other sectors.

The National Disability Rights Machinery shall be constituted by:

- (a) Accounting officers and/or designated disability rights coordinators of the Departments of Planning, M&E, Public Service and Administration, National Treasury, Women, International Relations and Cooperation, Statistics South Africa, and will be chaired by the department in which the national disability rights coordinating mechanism is placed;
- (b) Accounting officers and/or designated disability rights coordinators of the departments chairing each of the FOSAD clusters. A disability rights forum must be established for each FOSAD cluster to facilitate mainstreaming of disability into all issues presented to the cluster;
- (c) Accounting officers of national disability organisations; and
- (d) Additional technical expertise will be sourced from research institutions, independent consultancies, institutions of higher education, organised business and labour sectors, as well as international development and human rights agencies.

Provincial Disability Rights Machineries will report to the Provincial Executive Councils and Premiers' Coordinating Forums, and will be constituted by:

- 1. Provincial disability rights coordinating mechanisms;
- 2. Disability Rights managers from each provincial government departments and public entities;
- 3. Regional offices of national government departments;
- 4. South African Local Government Association;
- 5. District municipalities and metropolitan councils;

- 6. Local municipalities;
- 7. Provincial disability rights organisations; and
- 8. Provincial offices of institutions promoting democracy;

Additional expertise can be sourced from research institutions, institutions of higher education, organised business and labour sectors based in the respective provinces.

Local municipalities and metropolitan councils must establish disability rights consultative forums, with representation by, among others:

(a) All disability organisations operating within the municipal boundaries;

- (b) The disability representatives of every ward committee;
- (c) Senior management of all municipal departments; and
- (d) Secretariat services must be provided by the designated disability rights coordination mechanism within the municipality.

The roles and functions of the municipal disability rights consultative forums include:

- a. Providing a clearing house for disability priorities for inclusion in municipal integrated development plans and budgets;
- b. Monitoring implementation of the WPRPD at municipal level; and
- c. Providing advice to local Councils and IDP Steering Committees on the promotion and protection of the rights of persons with disabilities.

5.10.2 Roles and Functions of Disability Organisations

Organisations of and for persons with disabilities play a central role in advancing the implementation, as well as monitoring of the WPRPD. Their functions include:

- (a) Supporting the empowerment of their members and constituencies through human rights education campaigns;
- (b) Supporting the implementation of the WPRPD;
- (c) Monitoring implementation of the WPRPD.

A Civil Society Disability Rights Monitoring Fund must be established to support the monitoring responsibilities of representative organisations of persons with disabilities.

Partnership are essential: 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.

5.10.3 Deployment Strategy

A cadre policy as a political mechanism may take one of two forms:

- 1. **Cadre deployment**: The appointment by a government's governing party of a loyalist to an institution, as a means of circumventing public reporting-lines and bringing that institution under the control of the party, as opposed to the state. It involves the creation of a parallel power-structure to a constitution, so that party members answer first to the party and second to the public. In turn, that party advances its own interests ahead of those of the public.
- 2. **Cadre employment**: Economic patronage dispensed to individuals, companies and agencies, by the government, not on merit, but on the basis that they enjoy some political connection to the governing party⁷².

In the public service "cadre deployment", has already struck down as illegal, has prejudicial consequences for the promotion of constitutionalism and has been declared by the High Court. However, deployment continues after the High Court has characterized it as illegal and unconstitutional is indicative of movement away from the rule of law and the constitutional requirements for good governance⁷³.

The public administration provided for in the Constitution should exist to render services to all people in a manner which is impartial, fair, and equitable and without bias. [s 195]. It must loyally execute the lawful policies of the government of the day [s 197].

The State can hardly respect, protect, promote and fulfil the guaranteed human rights of all, as it must do in terms of the Bill of Rights, if deployed cadres are instead pursuing the purpose of the deploying authority.

The African National Congress (ANC) has justified cadre deployment by arguing that the 'deepening general crisis of the apartheid regime, the mass revolutionary actions of the oppressed masses inside South Africa and developments internationally confront the ANC with great challenges. Under conditions of fascist state terror and violence the Movement is called upon to lead the people in raising the level of struggle to that of a people's war for seizure of power. We also need to mobilize the international community to intensify its support for our struggle and for the complete isolation of racist South Africa'⁷⁴.

To effectively carry out these and other crucial tasks the Movement has to strengthen itself. One of the basic challenges we face in this context is that of formulating and implementing a coherent and systematic cadre policy. Delegates` Additional Recommendations in Plenary Cadre policy should include discipline of

⁷² Available at https://en.wikipedia.org/wiki/Cadre (politics)

⁷³ Hoffman, P.

⁷⁴ <u>https://web.archive.org/web/20160304055527/http://www.anc.org.za/show.php?id=134</u>

all cadres as a prime quality in the definition of a cadre. In the words of our President, `discipline is the mother of victory`⁷⁵.

There may be merit in developing an affirmative action policy that ensures that persons with disabilities are 'deployed' in order to achieve equality, equity, and other legislated measures. However, the constitutionality of such policy must be ascertained prior to adoption.

END OF CHAPTER

⁷⁵ https://web.archive.org/web/20160304055527/http://www.anc.org.za/show.php?id=134

POINTS TO PONDER/QUESTIONS TO CONSIDER

- Provide a step by step application of the right to self-representation
- How should self-representation be interpreted and defined?
- What should be the main objectives of self-representation?
- Should self-advocacy be considered as part self-representation?
- Should there be legal limitation and exceptions to the right to self-representation?
- Should rights and services be provided within the specific framework of selfrepresentation?
- How should self-representation be assessed and reported on?
- What should be the specific roles and responsibilities of government and all stakeholders including consultative platforms, deployments and report back
- What should be the institutional arrangements for the right to selfrepresentation including responsibilities, functions and duties of consultative platforms or committees
- What should be the criteria for appointments on platforms including deployment, selection criteria, and political affiliation and clearing house for the disability sector?
- How should the report on activities of representatives be compiled and submitted both at national, provincial and local forums
- What is the nomination procedure for deployees and representatives including their functions and responsibilities
- Should representatives be accredited and how should they be removed from their areas of representation
- What should be the dissolution criteria of representative platforms
- How should legal recourse to the right to self-representation be effected and what should be the necessary remedies

CONCLUSION

"Everyone is equal before the law and has the right to equal protection and benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken."

The Constitution of the Republic of South Africa, 1996

This framework provides guidance for the embedding self-representation within the context of enhancing the representative voice of persons with disabilities in all aspects of community life in order to secure the right to equal access and participation for all citizens and residents in South Africa, regardless of age, gender, ability, religion, culture or language.