



**MINISTRY IN THE PRESIDENCY FOR WOMEN, YOUTH AND PERSONS WITH DISABILITIES  
REPUBLIC OF SOUTH AFRICA**

**Private Bag X 931 Pretoria 0001: Tel: 012 3590013**

**PRELIMINARY REPORT ON THE RIGHTS OF PERSONS WITH ALBINISM FOR  
VISIT TO SOUTH AFRICA BY THE UNITED NATIONS INDEPENDENT EXPERT  
ON THE ENJOYMENT OF HUMAN RIGHTS BY PERSONS WITH ALBINISM**

**MS IKPONWOSA ERO**

**16 – 26 September 2019**

**REPORT PREPARED BY**

**DEPARTMENT OF WOMEN, YOUTH AND PERSONS WITH DISABILITIES**

## EXECUTIVE SUMMARY

### Introduction

Ms Ero, the Independent Expert (IE) on the enjoyment of human rights by persons with albinism will be conducting a fact-finding visit from the 16 - 26 September 2019.

The key focus areas during the IE's fact-finding visit will include among others:

- Engaging in dialogue and consulting with national and provincial officials from governments and other relevant stakeholders, including United Nations agencies, programmes and funds, regional human rights mechanisms, and national human rights institutions;
- To identify, exchange and promote good practices relating to the realisation of the rights of persons with albinism and their participation as equal members of society;
- To promote and report on developments towards and the challenges and obstacles to the realisation of the enjoyment of human rights by persons with disabilities in South Africa;
- To gather, request, receive and exchange information from relevant sources, including persons with albinism and their representative organisations, and other civil society organisations, on violations of the rights of persons with albinism; and
- To raise awareness on the rights of persons with albinism and to combat stereotypes, prejudices and harmful traditional practices and beliefs that hinder their enjoyment of human rights and participation in society on an equal basis with others.

Recognizing the compounded vulnerability of people with albinism, the South African Government, partnering with the Albinism Society of South Africa, convened the First National Conference of Persons with Albinism (2013) as a direct response to the UN Human Rights Council Resolution 23/13. The Conference took forward the recommendations contained in the report published by the Office of the High Commissioner on Human Rights on the Promotion of the Rights of Persons with Albinism. Through a consultative process, the **EKURHULENI DECLARATION ON**

**THE RIGHTS OF PERSONS WITH ALBINISM, 2013** (the Declaration) was developed and adopted by the Conference.

The purpose of this report is to consolidate a baseline on service delivery to persons with albinism. It is necessary to read this report together with South Africa's Initial Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities (Annexure A) and South Africa's Response to the UN List of Issues (Annexure B).

In preparation for the official visit by the Independent Expert to South Africa, an interdepartmental committee was established, co-chaired by the Department of International Relations and Cooperation and the Department of Women, Youth and Persons with Disabilities. A list of participating institutions is attached at Annexure C. A participatory and consultative process was adopted where national departments were requested to submit information with the guidance of a reporting template.

A broad legislative environment is outlined in the report that forms the basis for provisions of human rights for persons with albinism. This includes, but is not limited to, the Constitution of South Africa (1996), the Promotion of Equality and Prevention of Unfair Discrimination Act (2000), the UN Convention on the Rights of Persons with Disabilities (2007) and the White Paper on the Rights of Persons with Disabilities (2015).

The report provides available information on the equality and non-discrimination, awareness-raising, access to justice, education, health, social protection, cultural life as well as statistics and data collection.

The reality is that government's information systems do not disaggregate information by persons with albinism, as the administrative burden of disaggregating information by types of disabilities is impractical. There are varying models of disability utilised by government that include the social and medical models. In order to improve the manner in which government collates data with regard to persons with albinism, Statistics South Africa is currently in the process of harmonising the measure of disability across all government departments.

## Recommendations

Although there are commendable initiatives in departments, including partnerships with civil society, it is evident that services for persons with albinism is uneven. As such the following recommendations have been proposed by the Steering Committee during its assessment of the status quo and moving forward:

- 1.1. South Africa should adopt and implement the Regional Action Plan on Albinism in Africa (2017 – 2021).
- 1.2. Executive authorities should champion the inclusion of persons with disabilities at a sectoral and programmatic level.
- 1.3. All accounting officers should ensure the inclusion of persons with albinism at a programmatic level.
- 1.4. South Africa should develop and adopt a National Strategy on Strengthening Protection of Persons with Albinism.
- 1.5. All Departments should report annually on the EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM (2013) to track progress and trends.
- 1.6. The Department of Health should conduct an audit of availability of critical primary and secondary health services to persons with albinism in all provinces.
- 1.7. The National School of Government should ensure that its Disability Mainstreaming training modules emphasises diversity within disability, with particular reference to persons with albinism.
- 1.8. The Department of Planning, Monitoring and Evaluation should measure all government social cohesion programmes for impact on the lives of persons with albinism.
- 1.9. The Departments of Sports, Arts and Culture; Justice and Constitutional Development as well as Traditional Affairs, in partnership with the SA Human Rights Commission and the Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities, should roll-out awareness raising programmes on the rights of persons with albinism within the larger context of the right to equality for persons with disabilities.

- 1.10. STATISTICS SA should develop a model to strengthen disability statistics and administrative data.
- 1.11. The Justice, Crime Prevention and Security Cluster should scale up targeted measures to protect the rights of persons with disabilities.

## ACRONYMS

Independent Expert on the enjoyment of human rights by persons with albinism (IE)

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

The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 (PEPUDA)

The South African Human Rights Commission (SAHRC)

UN Convention on the Rights of Persons with Disabilities (CRPD)

Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa

The Department of Justice and Constitutional Development (DoJCD)

Gender Based Violence (GBV)

Department of Arts and Culture (DAC)

Screening Identification Assessment and Support (SIAS)

National Student Financial aid Scheme (NSFAS)

The Department of Higher Education and Training (DHET)

Higher and Further Education Disability Services Association (HEDSA)

National Social Inclusion Forum (NSIF)

The Department of Health (DoH)

South African Social Security Agency (SASSA)

The Early Childhood Development (ECD)

Independent Monitoring Mechanism (IMM)

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## 2. INTRODUCTION

### 2.1. Background

In October 2017, Ms Ero, the Independent Expert (IE) on the enjoyment of human rights by persons with albinism, requested a country visit to South Africa which was officially accepted at UNGA71. Ms Ero was subsequently invited by the former Minister Shabangu to visit in September 2018. However, Ms Ero was already committed to visit Kenya during the dates proposed by South Africa. Eventually the dates of 16 - 26 September 2019 was finalised.

The key focus areas during the IE's fact-finding visit will include among others:

- Engaging in dialogue and consulting with national and provincial officials from governments and other relevant stakeholders, including United Nations agencies, programmes and funds, regional human rights mechanisms, and national human rights institutions;
- To identify, exchange and promote good practices relating to the realisation of the rights of persons with albinism and their participation as equal members of society;
- To promote and report on developments towards and the challenges and obstacles to the realisation of the enjoyment of human rights by persons with disabilities in South Africa;
- To gather, request, receive and exchange information from relevant sources, including persons with albinism and their representative organisations, and other civil society organisations, on violations of the rights of persons with albinism; and
- To raise awareness on the rights of persons with albinism and to combat stereotypes, prejudices and harmful traditional practices and beliefs that hinder their enjoyment of human rights and participation in society on an equal basis with others.

Recognizing the compounded vulnerability of people with albinism, South Africa convened the National Conference of Persons with Albinism (2013) as a direct response to the UN Human Rights Council Resolution 23/13. This was hosted in partnership with the Albinism Society of South Africa. This was a significant milestone

that brought together over 250 delegates with albinism, including 90 children with albinism drawn from special and ordinary schools across all nine provinces.

The Conference took forward the recommendations contained in the report published by the Office of the High Commissioner on Human Rights on the Promotion of the Rights of Persons with Albinism. Through a consultative process, the **EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM, 2013** (the Declaration) was developed and adopted by the Conference.

South Africa approved the White Paper on the Rights of Persons with Disabilities and its Implementation Matrix in 2015. This is regarded as the first step towards the domestication of the UN Convention on the Rights of Persons with Disabilities. On approval, the Cabinet instructed that annual progress reports be submitted on the status of implementation. Thus far the First Annual Progress Report was approved and published together with the Declaration.

It is important to note that since the May 2019 Elections, President Cyril Ramaphosa announced the reconfiguration of Government. This resulted in the establishment of the Ministry of Women, Youth and Persons with Disabilities (DWYPD). This Ministry is located in the Presidency. Minister Maite Nkoana-Mashabane and Deputy Minister Hlengiwe Mkhize head this portfolio. Furthermore, the Presidential Working Group on Disability has been revived and will convene once per year with its attendant technical working groups undertaking strategic tasks on an ongoing basis.

In April 2019, South Africa signed the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa. It is expected to be submitted to Parliament for purposes of ratification in the final quarter of 2019.

It is important that this report is read together with South Africa's Initial Country Report on the Implementation of the UN Convention of the Rights of Persons with Disabilities of 2014 (Annexure A) as well as South Africa's Response to the List of Issues of 2019 (Annexure B).

## 2.2. Purpose of the Report

The purpose of this report is to provide baseline information on the status of persons with albinism, particularly in preparation for the visit by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, Ms Ikponwosa Ero, to South Africa from 16-26 September 2019.

## 2.3. Research Methods

Having given due consideration to the Ekurhuleni Declaration on the Rights of Persons with Albinism (2013), Regional Action Plan on Albinism In Africa (2017 to 2021), the OHCHR Questionnaire on Persons with Disabilities, the UN Committee's Concluding Observations and the White Paper on the Rights of Persons with Disabilities, a reporting template was developed and circulated to relevant departments.

South Africa adopted a participatory process in collecting info and developing the report. There was validation from the data sources and sign off by Minister Nkoana-Mashabane on the 20 August 2019.

## 3. BROAD LEGISLATIVE ENVIRONMENT

South Africa is well-known for its progressive legislative context. Listed below are key directives that should benefit persons with albinism:

1. The South African Constitution (1996)
2. The Integrated National Disability Strategy (1997)
3. The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000
4. The Employment Equity Act (1998)
5. UN Convention Rights of Persons with Disabilities (2007)
6. National Social Cohesion Strategy (2012)
7. The Ekurhuleni Declaration on the Rights of Persons with Albinism constitutes the current national programme of action for the eradication of all forms of discrimination against persons with albinism (2013)
8. Prevention and Combating of Trafficking in Persons Act (2013)
9. Policy on Screening, Identification, Assessment and Support (2014)

10. The Legal Aid South Africa Act 39 (2014)
11. Protocol for the Management and Reporting of Sexual Abuse and Harassment in Schools
12. White Paper on the Rights of Persons with Disabilities (2015)
13. The Trafficking in Persons Act National Policy Framework (2019).
14. The Witchcraft Suppression Act, 1957
15. Signed AU Protocol on Rights of Persons with Disabilities (2019)
16. South African Schools Act 84 of 1996
17. National Action Plan to combat Racism, Racial Discrimination, Xenophobia and Related Intolerance (2019)

#### 4. DISCUSSION

The following section focuses on key rights for persons with albinism and the provision thereof.

##### 4.1. Equality and Non-discrimination

South Africa pursues a substantive rather than formal approach to equality. The Bill of Rights in the South African Constitution (1996) is premised on the principle of 'equality of outcomes' for marginalised groups which includes persons with albinism at risk of multiple and intersectional discrimination on the basis of gender, age, type and severity of disability, sexual orientation, geographical location and socio-economic status.

The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 (PEPUDA) supports the elimination of discrimination by compelling the provision of reasonable accommodation for persons with disabilities. All high courts and magisterial courts are designated as equality courts. This recourse mechanism remains underutilised due to various barriers that include awareness of this mechanism, sensitisation of judiciary and communication formats.

The White Paper on the Rights of Persons with Disabilities of 2015 (WPRPD) prioritises protecting the rights of persons at risk of compounded marginalisation.

In March 2019, the Cabinet approved the National Action Plan to Combat Racism, Racial Discrimination, Xenophobia and Related Intolerance (NAP) for implementation in the next Medium Term Strategic Framework: 2019-2024.

This focuses on equal opportunities, inclusion and redress. This implies building people's capabilities through access to quality education, health care and basic services, as well as enabling access to employment, and transforming ownership patterns of the economy. The realisation of this outcome is dependent on their entire value chain of government. This will be done in collaboration and coordination of government programmes, particularly those driving access to services, socio-economic opportunities and empowerment for maximum impact; and mainstreaming of the target groups (women, children, youth, disability) into the facet of planning, budgeting, monitoring and reporting.

The South African Human Rights Commission (SAHRC) has a constitutional mandate as an independent body to promote, protect and monitor the rights of all people in South Africa. It is required to report on the state of equality in the country. The SAHRC is currently in the process of establishing the Independent Monitoring Mechanism (IMM) on disability rights.

The domestication of the UN Convention on the Rights of Persons with Disabilities (CRPD) is currently underway and is earmarked as a medium term deliverable.

#### 4.2. Awareness-raising

There is currently no coherent national strategy for awareness-raising that speaks to coordination or impact. However, South Africa is in the process of developing a national framework to address this gap.

The measures taken to create awareness on the rights of persons with albinism include the following:

- The State funds the Albinism Society of South Africa to strengthen its organisational capacity as well as running awareness programmes with particular emphasis on traditional contexts.
- In terms of cultural harmful practices, the majority of disability rights advocacy campaigns take place during national albinism awareness month (September), the national disability rights awareness month (November) and human rights month (March).

- The Department of Justice and Constitutional Development (DoJCD) is currently conducting ongoing multi-sectoral public awareness and education campaigns on the equality courts in at least four provinces.
- Public Education materials on legislation, access to courts and police services were converted into accessible formats, inclusive of braille, large print and audio.
- In 2017 November the South African Police Service conducted five days albinism awareness campaigns in Northern KwaZulu-Natal in a form of door to door and border visits, in addition to the main event.
- In the same year, Commissioner Mazibuko, founder of Albinism Society of South Africa was afforded a platform on SAPS On Duty Call TV Program to talk to seriousness of the security challenges faced by persons with albinism.
- “Mama I want the Black you Are” is a play that is supported by the Department of Arts and Culture (DAC).
- In 2018, the DAC collaborated with the Mud Parables, an arts and drama organisation based in the Western Cape Province. It sponsored a play entitled “Testimonies of My Life”. This is a drama based on a true story testimony expelling myths and highlighting the stigma and discrimination faced by persons with albinism. The play toured schools and shopping malls to address and discuss the issues of stigma and acceptance.
- The DAC financially supported awareness campaigns on albinism with particular reference to ASSA and the Western Cape Hypo Pigment Foundation. The flagship programmes include the WE CAN ARTS FESTIVAL.
- In the same year, the DAC supported the Western Cape Hypo Pigment Foundation to launch Albinism month through a march and an interactive dialogue that included local government councillors, traditional leaders, traditional leaders, academia and the Tygerberg Hospital. The dialogue was captured by the media.
- A round table discussion was held at the Magnet Theatre in Cape Town. The Albinism month was themed “Shine Our Light”. The progressive work done by the traditional healer’s organisation “Sesiyakhula Njalo” was shared as it relates to condemning of the killings and murders of persons with albinism. The organisation rolls out campaigns on the rights of persons with albinism.

- The DAC runs awareness raising campaigns, community conversation and dialogues on various themes such as unity, equity, belonging, justice and access. There are also interactive panel discussions that are broadcast live on the radio. The Department launched its #AlbinismActivismCampaign on 4 May 2018.
- The Department of Justice and Constitutional Development (DoJCD) has partnered with a non-governmental organization, Khulisa Social Solutions (Khulisa), to host a National Summit on the 14-15 November 2019. The Unit will offer financial support to provide the venue and transportation and accommodation for approximately 18 people from across South Africa (2 persons per province). Khulisa is a South Africa registered (1998) Non-Profit Company, specialising in social justice, which has over the past two years, been working with persons with albinism. It also focuses on organisations in Southern Africa. The intention is to gain a greater understanding of the predicament persons with albinism are in, and to ascertain how effectively civil society and government can assist in strengthening the fight against the stigmatisation of persons with albinism through advocacy, public education, accountability and swift recourse to the law.
- The DoJCD and Khulisa issued a press statement on the 13 June 2019 in recognition of the International Day for Persons with Albinism. Subsequent to this a DoJCD representative was invited to comment on the issue of access to justice for persons with albinism by a few radio stations; for example **TRU FM radio** station 89.3-107.8 MHz FM and Power FM on 98.7.
- The DoJCD participated in a mediation workshop hosted by Khulisa Social Solutions in Rosebank on Saturday the 1<sup>st</sup> of June 2019. The purpose of the workshop was to assist families to reunite with their loved ones who have albinism; to thrive and integrate as wholesome family units within a compassionate and an empathetic societal group.
- The DoJCD will host 6 workshops on the Sensitization of Court Officials on matters related to persons with disabilities including persons with albinism as regards the rights, needs and challenges experienced by persons with albinism and other disabilities with accessing the services offered by the Department and the courts.

- The DoJCD conducts general awareness campaigns to sensitise communities on Trafficking in Persons issues which were undertaken by governmental departments in partnership with civil society.
- The Department of Social Development offered strategic and in-kind support to the organisation – Albinism Advocacy for Access, led by CEO – Mr Mpho Tjope, at the launch of the campaign #ICANBE on the 13<sup>th</sup> June 2019.
- The Department of Social Development subsidises the Albinism Society of South Africa through an annual subsidy to support operational costs and campaigns within the context of strengthening the representative voice of persons with albinism.
- The appointment of two members with albinism on the Presidential Working Group on Disability in 2016.
- There is a repository of studies available to all departments for planning purposes, these include:
  - Msomi, V.D. (2014). Stark white: experiences of learners with albinism (LWA) in primary and secondary schools in the Umlazi District. Thesis submitted in partial fulfilment of the requirements of Master of Educational Psychology, Discipline of Educational Psychology, School of Education Studies, University of KwaZulu-Natal.
  - Mswela, M.M. (2016). A selection of legal issues relating to persons living with albinism. A thesis submitted in accordance with the requirements for the degree of Doctor of Laws, University of South Africa.
  - Ikuomola, A.D. (2015). 'We thought we will be safe here': Narratives of Tanzanian Albinos in Kenya and South-Africa. *An International Multidisciplinary Journal, Ethiopia*, 9(4), 37-54.
  - Mpumalanga Provincial Legislature. (2017). *Report of the Select Committee on Public Participation, Petitions and Members' Legislative Proposals on Parliament for People with Albinism held on 21 June 2017, Mpumalanga Provincial Legislature Chambers*. Nelspruit: Mpumalanga Provincial Legislature.

### 4.3. Access to justice

Measures taken to provide access to justice include the following:

- The South African Police Services (SAPS) National Instruction 2/2012 on Victim Empowerment
- SAPS National Instruction 7/1999 on Domestic Violence
- SAPS National Instruction 3/2008 Sexual Offences
- SAPS National instruction 2/2010 on children in need of care and protection
- SAPS Standing Operating Procedure on Combating of Trafficking in Persons
- SAPS Standing Operating procedure on Vulnerable Children
- SAPS Standing Operating Procedure on Policing of LGBTI+
- There are one thousands and seventy one (1071) dedicated victim friendly rooms at police stations countrywide. Police stations without dedicated victim friendly rooms use alternative offices for private statement taking and for further referral for psychosocial support of the victim.
- SAPS Guidelines on Policing of Persons with Disabilities was developed and waits for approval.
- SAPS Vulnerable Groups Learning Program was reviewed and awaits approval.
- Persons with disabilities including persons with albinism are regarded as a vulnerable segment of our community. Legal Aid SA may provide legal aid for the protection of constitutional rights to progressively implement section 7 of the Constitution subject to availability of resources. Legal aid may be provided to all persons who qualify for such assistance in civil matters. Legal aid is available to sentenced or detained person or an accused person if substantial injustice would result subject to such persons qualifying in terms of the regulations.
- In line with the United National Convention Against Transnational Organised Crimes (commonly known as the Palermo Protocol), the SA

Government enacted the Prevention and Combating of Trafficking in Persons Act, No. 7 of 2013. The Act outlines legal prescripts for arresting and prosecution of perpetrators of TIP as well as required support services for the victims. The Act includes a broad definition of trafficking and sets out various trafficking-related offences that are subject to harsh penalties.

- The South African government has already put structures in place at national and provincial levels.
- A National Inter-sectoral Committee on Trafficking in Persons was established. It comprises representation from national departments, amongst others, Justice and Constitutional Development, Health, Home Affairs, International Relations and Cooperation, Labour, Social Development, Women, the SAPS, the National Prosecuting Authority as well as civil society organisations. The Committee leads the implementation and administration of the Act at a national government level.
- Provincial Task Teams on Trafficking in Persons were also established as well as Provincial Rapid Response Teams to attend to operational matters relating to suspected complaints and pending cases of trafficking in persons and providing support to victims.
- An integrated and holistic Immigration Policy is receiving attention and the Justice Crime Prevention and Security Cluster departments have made the combating of trafficking of persons a priority in the Cluster's activities to ensure **all** persons in South Africa Are and Feel safe.
- The draft Prevention and Combating of Hate Crimes and Hate Speech Bill is currently before the Cabinet. It makes particular reference to persons with albinism. The objects of this Bill are to—
  - (a) give effect to the Republic's obligations regarding prejudice and intolerance as contemplated in international instruments;
  - (b) provide for the prosecution of persons who commit offences referred to in this Act and provide for appropriate sentences;
  - (c) provide for the prevention of hate crimes and hate speech;
  - (d) provide for effective enforcement measures;

- (e) provide for the co-ordinated implementation, application and administration of this Act;
- (f) combat the commission of hate crimes and hate speech in a co-ordinated manner; and
- (g) gather and record data on hate crimes and hate speech.

The Draft Prevention and Combating of Hate Crimes and Hate Speech Bill provides for the Minister responsible for the administration of Justice to prescribe information that must be collected and collated by the South African Police Service and the National Prosecution Authority.

#### 4.4. Right to Education

##### **Early Childhood Development**

The Early Childhood Development (ECD) Policy was approved by Cabinet in December 2015. The policy advocates that securing the universal right of children with disabilities to ECD and as such should be provided as a public good and be universally available, inclusive and comprehensive.

In order to ensure that this service is provided to children with disabilities, it is necessary to ensure that adequate resources are allocated for universally designed infrastructure, delivery of appropriate inclusive quality services; and clear norms and standards for implementation. The mainstreaming of children with disabilities at ECD level is encouraged, where specialist support should be made available. This further includes investment in training a sufficient number of qualified early childhood development practitioners and related professionals to provide quality and appropriate early childhood development services to children with disabilities and their families. The ECD Financing Strategy includes a disability inclusion top-up allocation to incentivise inclusion of children with disabilities, inclusive of children with albinism, in community based ECD centres and programmes. To this end social protection tracks the coverage of children with disabilities in ECD in terms of inclusion, attendance, training of practitioners and building of accessible infrastructure.

## **Basic Education**

The South African Schools Act 84 of 1996 and Education White Paper 6: Special Needs Education: Building an Inclusive Education and Training System provides guidelines on how to make the entire education system more inclusive.

The WPRPD has a specific focus area directing action towards extending reasonable accommodation consistently across all sectors. A national Framework on Reasonable Accommodation for Persons with Disabilities has been finalised and is awaiting Cabinet approval by April 2019.

Schools provide learners with the necessary assistive devices so that they are able to access the curriculum, this is also coupled with accommodations and concessions, which must be applied for by the school.

Learners in schools are supported with assistive devices and technology to access the curriculum. This is provided by the department/school. Devices include screens in the classroom to enlarge books or worksheets and large font printing of workbooks. The support needs of the learners are prioritised through the application of the Screening Identification Assessment and Support (SIAS) policy, 2014. The draft policy on Accommodations and concession also make provision for learners to apply for adapted materials, extra time, or other differentiated measures.

Schools have introduced hats as part of their uniform to protect learners from the sun and in addition, learners receive sun screen as part of the package.

In some parts of the country children with albinism are educated in special schools catering for visual impairment. The increased awareness is resulting in adopting more inclusive approaches, where children with albinism receive their education in mainstream schools. This may be attributed to the fact that some families and communities have realised that education is a human right, which enables children with albinism to contribute in society in the same way as others.

However, in some rural communities, such as the KwaZulu-Natal midlands, where there are no schools for the blind in the proximity, children with albinism have always attended mainstream schools.

Schools have access control measures to screen people who come to ask for children to ensure safety for learners. In addition, schools where learners use public transport open their gates earlier than their starting times to ensure that learners do not have to wait at the gate.

There are a number of barriers prevalent in the schooling system, which include the following:

- **Systemic barriers** e.g. overcrowded classrooms, inaccessible school buildings for the persons / children with disabilities, lack of basic and appropriate learning materials, exclusionary policies, attitudes and practices etc.
- An audit conducted in May 2013 revealed many schools with equipment which are not properly maintained and are supplied by vendors who do not provide appropriate software.
- **Societal barriers** e.g. poverty, safety and security, children affected and infected by HIV/AIDS, child-headed households, children living in the streets, children in conflict with the law etc.
- **Pedagogical barriers** e.g. inappropriate teaching methods as well as learning and teacher support material, unqualified and under-qualified teachers, inappropriate assessment procedures, lack of support for teachers etc.
- **Intrinsic barriers** e.g. barriers experienced by learners with neurological, physical, sensory and cognitive disabilities or psychosocial and emotional difficulties etc. With specific reference to children with albinism, enabling access include the provision of assistive devices where applicable and necessary to ensure that children have access to the curriculum.
- **Diversity in the Classroom** simply means that learners come from different backgrounds; that differences should be embraced, valued, respected and be used positively, and that every classroom has inherent differences along socio-economic, language, culture, ethnicity, race, ability contexts. As part of the Life Skills curriculum, children are taught to celebrate and respect difference as part of ensuring an environment where all children can feel that they belong.

- ***Different Learning Styles and Needs*** simply means that there are a multiple intelligences and styles of learning for learners with hearing, speech, visual and coordination difficulties; for learners living in poverty; for learners with health, emotional and behaviour difficulties; for learners struggling to remember what has been taught; for learners requiring assistive devices and adapted materials; and for learners with difficulty in reading and writing.
- ***Inconsistencies in implementation of the Inclusive Education Policy between provinces.***

Managing diversity in the classroom

Requires of teachers to:

- Recognise bias and or stereotypes against certain learners
- Treat and respect each learner as an individual
- Avoid use of biased language that undermines certain groups
- Refrain from remarking and making of assumptions about learner experiences
- Consider unique needs of learners during lesson / programme design
- Constantly re-evaluate methods of teaching and assessing
- Always vary approaches, methodologies and strategies
- Create opportunities for all learners to participate in the learning process.

## ***Interventions***

### **Braille, Enlargement and Distribution of Workbooks**

- All work book 1's have been adapted and delivered to Printers. Toolkits will be delivered per subject – order already issued by DBE;
- Grade R books 1 and 2 have been brailled and delivered;
- Grades 1, 4, 5 and 6 Maths book 1 workbooks have been brailled and delivered;
- Prescribed list of books have been adapted and is in the process of being brailled - Grades 1-6 book 2's Home Language and Mathematics; book 1&2 Life Skills for Foundation Phase; book 1&2 Maths grades 7-9; book 1&2 English

First Additional Language (EFAL) for grades 4-6; books 1&2 Natural Sciences and Technology for grades 4-6.

- The Department of Basic Education is providing Learning and Teaching Support Materials for the 23 schools of the blind, where children with albinism are largely accommodated.
- Learning and Teaching Support Materials and other types of support/intervention is also provided to learners in mainstream schools, and this is done through the process of the SIAS.

Teacher Development Initiatives by 2014 have included:

- Teacher training programmes were done and developed with experts in: Visual impairment – 2012 and un-contracted Braille in December 2012
- Development of a Teacher Guide that contains specialised skills in visual impairment including the use of assistive devices and technology.
- The collaborative partnership between Department of Basic Education and Department of Higher Education and Training has led to the development of specialised university qualifications in education. The University of Pretoria is developing a specialised education course on visual impairment. The module is to address matters relating to the use of assistive devices and technology, learner support, reading braille and adaptation of learner workbooks containing worksheets (informal and formal work) into braille and large font print. It is envisaged that the Department’s bursary scheme, called Funza, Lushaka will fund all teachers who take courses in specialised areas.

<b>Province</b>	<b>Number of learners with Albinism in Special Schools</b>	<b>Number of learners with Albinism in Mainstream Schools</b>
Gauteng	279	Data is not available on the South African School Administration and Management Systems (SASAMS)
KwaZulu-Natal	153	216
Limpopo	138	182
Mpumalanga	4	32
Northern Cape	3	11
Western Cape	67	No data available

*Data provided by Provincial Education Departments-2019. NW, FS and EC did not provide any data*

## **Post – School Education and Training**

Both the Policy Framework for the Realisation of Social Inclusion in the Post-School Education and Training System and the Strategic Policy Framework on Disability for the Post-School Education and Training System are measures that address all forms of exclusion including Albinism in the Post School Education and Training (PSET) System.

In 2018, the National Social Inclusion Forum (NSIF) was established as a consultative structure on social inclusion implementation. Higher and Further Education Disability Services Association (HEDSA) was invited as a stakeholder.

Albinism is thus recognised as both a Disability and a Human Rights issue in the PSET System in line with national and international standards.

The Department of Higher Education and Training (DHET) provides support through an infrastructure grant to institutions and financial support for indigent students, which include a reasonable accommodation grant to students with disabilities through National Student Financial aid Scheme (NSFAS).

Post school education and training institutions fund the staffing of disability units, but this is insufficient and will require funding from DHET in future. Disability units have traditionally been established due to the demand, and have therefore not formed part of the establishment costs of universities. There are currently no national guidelines or norms and standards for the establishment of disability units.

Disability units typically provide the following support services in across various degrees:

- Conversion of textbooks to electronic formats
- Access to electronic formats with ZoomText or conversion to braille
- Front of class seating
- Extra writing time during exams & enlarged fonts/Braille question papers
- Extra writing time (most disabilities); separate room; use of a computer; scribes/amanuensis

- HEDSA was formed in 2007 as a collective voice for people working in disability units in higher education institutions. HEDSA is an advocacy and rights-based organisation that lobbies around issues of interest concerning students with disabilities by:
  - Stimulating and facilitating dialogue & critical reflection
  - Promoting equity, diversity and inclusivity in higher and further education institutions
  - Networking & cooperating with national bodies: HESA, CHE, NGOs
  - Supporting them in advocacy and disability-related areas of change management
  - Identifying current issues and areas of need
  - Undertaking achievable, affordable and appropriate projects
  - Encouraging research, collaboration and development
  - assisting NSFAS with the revision of their 2013 guidelines for reasonable accommodation support
  - Engagement with DHET for infrastructure funding for Disability Units.

#### 4.5. Right to Health

The Department of Health (DoH) has put the following measures in place:

- Sunscreen is available free of charge at clinic level to indigent persons with albinism as part of the Essential Drug List for Primary Healthcare. Primary healthcare facilities across the country report availability of sunscreen to persons with albinism. Anecdotal reporting by community-based organisations of persons with albinism however regularly report on supply outages at primary health care level, and the national Department of Health has confirmed that there is currently no reliable monitoring system in place to track availability at community level.
- Albinism Care Packs in one province (Gauteng), provided by the provincial Department of Social Development, thus far has been extended to include protective clothing and sunglasses, among others. A comprehensive survey to determine coverage is being considered.
- The DOH has a budget for the necessary free optical assistive devices for the H0 category patients and children/persons with disabilities in all facilities that render eye health services. Persons with albinism have access to free tint when

they get their spectacles within the Public Health System to minimize the visual impacts of photophobia. Provinces also have programmes where they provide persons with albinism with sunglasses.

- The DOH has capacity to diagnose and manage albinism from childhood to adulthood. A clinical protocol called PC101 is used to diagnose albinism and manage the clinical manifestations thereof.
- Persons with dermatological complications are referred to dermatologists who are located at tertiary health facilities for further management.
- Foveal hypoplasia is associated with albinism leads to poor vision in most cases; and if the patient is still unable to acquire functional vision following correction of refractive error and other conditions, the patient is referred to South African Social Security Agency (SASSA) for social grants.

#### 4.6. Adequate standard of living and social protection

All public services are available to all citizens including persons with albinism. On the aspect of social assistance, the country's social security provides care dependency grants, grant in aid and disability grants. The means test to qualify for grants follows a medical model. Although, this information is tracked, it cannot be disaggregated by persons with albinism.

#### 4.7. Participation in cultural life

The DAC has a Memorandum of Understanding with the Department of Traditional Affairs. The areas of collaboration include the eradication of negative cultural practices (including harvesting of body parts, trafficking of persons and witch-hunting), discrimination and the prevention of Gender Based Violence (GBV).

Although South Africa has a vibrant cultural and creative sector, there is currently no disaggregated data on the participation of persons with albinism. As indicated under Awareness-Raising, there are a number of social cohesion programmes that aim to promote national unity and identity.

#### 4.8. Statistics and data collection

South Africa adopted the Washington Set of Questions on Disability. Since the Census 2011, the short set of questions is used in surveys. This focusses on functional

limitations. Additionally, in large scale surveys, there is a question on reasonable accommodation.

The 2011 census findings show a national disability prevalence rate of 7,5%. Provincial variations show that Free State and Northern Cape provinces had the highest proportion of persons with disabilities (11%), followed by North West and Eastern Cape (10% and 9,6% respectively). Western Cape and Gauteng provinces showed the lowest percentage of persons with disabilities (5%). The population group profile shows that black Africans had the highest proportion of persons with disabilities (7,8%), followed by the white population group (6,5%).

Overall, persons with albinism is counted under the analysis of persons with disabilities. The Washington Group questions do not overtly measure persons with albinism, this therefore presents a challenge in using available statistics for planning programmes for persons with albinism.

There are discussions with STATISTICS SA to determine how this challenge may be overcome.

## 5. CONCLUSION

There is a sound legislative environment that is currently not translated to targeted, equitable planning, programming, budgeting and reporting on service delivery for persons with albinism. The focus is on transforming the accessibility and availability of services on demand.

It is clear that tracking systems do not disaggregate by persons with albinism. This is the status quo for persons with disabilities broadly as current information systems are based on functional limitations that correlate with the provision of reasonable accommodation.

Very few persons with albinism are affiliated to structured organisations and therefore collective self-representation through representative organisations of persons with albinism is limited.

One human rights violation, is one too many. There are low reported incidents of violence, abuse, mutilation, kidnapping, attempted kidnapping, trafficking and murder

of persons with albinism, therefore potential underreporting is a challenge. There have been discussions with regard to establishing a database for persons with albinism which may negate the safety issues.

The **EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM (2013)** is a comprehensive monitoring framework for the implementation of the rights of persons with albinism. However, national departments have not yet institutionalised reporting requirements, inclusive of service delivery at provincial level, that can yield information that will provide feedback for planning.

## 6. RECOMMENDATIONS

Having assessed the baseline information available on rights of persons with albinism, the following recommendations have been proposed by the Steering Committee during its assessment of the status quo and moving forward:

- 6.1. South Africa should adopt and implement the Regional Action Plan on Albinism in Africa (2017 – 2021).
- 6.2. Executive authorities should champion the inclusion of persons with disabilities at a sectoral and programmatic level.
- 6.3. All accounting officers should ensure the inclusion of persons with albinism at a programmatic level.
- 6.4. South Africa should develop and adopt a National Strategy on Strengthening Protection of Persons with Albinism.
- 6.5. All Departments should report annually on the EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM (2013) to track progress and trends.
- 6.6. The Department of Health should conduct an audit of availability of critical primary and secondary health services to persons with albinism in all provinces.
- 6.7. The National School of Government should ensure that its Disability Mainstreaming training modules emphasises diversity within disability, with particular reference to persons with albinism.
- 6.8. The Department of Planning, Monitoring and Evaluation should measure all government social cohesion programmes for impact on the lives of persons with albinism.

- 6.9. The Departments of Sports, Arts and Culture; Justice and Constitutional Development as well as Traditional Affairs, in partnership with the SA Human Rights Commission and the Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities, should roll-out awareness raising programmes on the rights of persons with albinism within the larger context of the right to equality for persons with disabilities.
- 6.10. STATISTICS SA should develop a model to strengthen disability statistics and administrative data.
- 6.11. The Justice, Crime Prevention and Security Cluster should scale up targeted measures to protect the rights of persons with disabilities.

## 7. Annexure A: South Africa's Baseline Country Report

8. Annexure B: South Africa's response to List of Issues to UN CRPD Committee

## 9. Annexure C: List of stakeholder participants