

REPORT OF THE SELECT COMMITTEE ON PUBLIC PARTICIPATION, PETITIONS AND MEMBERS' LEGISLATIVE PROPOSAL ON PARLIAMENT FOR PEOPLE WITH ALBINISM HELD ON THE 21st JUNE 2017 MPUMALANGA PROVINCIAL LEGISLATURE CHAMBERS

1. INTRODUCTION

The Constitution of the Republic of South Africa empowers the Mpumalanga Provincial Legislature with the responsibility, in terms of section 118(1), to facilitate public involvement in legislative and other processes of the Legislature and its committees. It further directs the Legislature to conduct its business, its sittings and committees in public.

As part of the mechanisms, the Rules and Orders of the Mpumalanga Provincial Legislature establishes and empower the Select Committee on Public Participation, Petitions and Members' Legislative Proposals (the Committee) to facilitate Parliament for People with Albinism which provide a platform for discussing critical issues of the sector in the Province.

The Committee tables this report, in terms of Rule 118 of the Rules and Orders, to give full account on the subsequent hosting of the 2017 Parliament for People with Albinism held at the Legislature Chambers on 21 June 2017 and recommend for its adoption.

2. OBJECTIVES

As part of strengthening the oversight role of the Legislature, the strategic objectives of the project are inter alia:

- To educate and share the information with the People with Albinism and Society.
- To educate and share information and create public awareness on matters of albinism.

- Facilitate a direct oversight exercise involving all the role players i.e. the Legislature, executive and the targeted beneficiaries in one sitting.
- Provide space for positive engagement on social matters of albinism
- To improve the oversight function on matters affecting people with albinism
- Create a common understanding in facilitating awareness of albinism

3. THEME

The Mpumalanga Provincial Legislature approved the Sectoral Parliament for People with Albinism, under the theme **“Celebrating 20 years of the Constitution”**

4. THEMATIC AREA

The Sectoral Parliament focused on the following thematic areas as enriching deliberations and consolidating gains;

- The rights of People with Albinism.
- Create awareness on albinism.

5. METHOD OF WORK

The Cross-Functional Task Team was established and assigned a function to work on the hosting of the Parliament for People with Albinism. The conceptualization on the event was driven by office of the Speaker since the program did not allow for committee meetings. The mobilisation was targeting the attendance of two hundred (200) participants from Ehlanzeni district, Gert Sibande and Nkangala district.

6. STAKEHOLDERS

The following stakeholders were central in the identification, invitation and hosting of the Parliament for People with Albinism

- Mpumalanga Provincial Legislature
- Albinism Society of South Africa
- Department of Social Development
- Nkomazi Municipality

- Department of Education
- Department of Health

7. ADDRESSES

7.1. OPENING AND WELCOMING REMARK: MRS. BT SHONGWE, MPL SPEAKER OF THE MPUMALANGA LEGISLATURE

Hon BT Shongwe welcomed all participants to Parliament for People with Albinism on behalf of the 5th Mpumalanga Provincial Legislature and hailed the event a historic occasion, the first Parliament for People with Albinism in all nine Legislatures.

She reiterated the fact that the Legislature is guided by the Constitution of the Republic of South Africa and in fulfilling its core mandate. She acknowledged the sterling role played by Select Committee on Public Participation, Petitions and Members Legislative Proposals led by Hon JL Nghondzweni for successfully coordinating this Sectoral Parliament.

She asserted, “it is an opportunity for Mpumalanga Legislature to reflect on whether we are winning the battle of protecting persons with albinism. The Legislature condemns and is concerned about continuing attacks against persons with albinism. The killing, trafficking and abduction of persons with albinism violate the right to life, liberty and security and the prohibition of torture and ill-treatment. The continued attacks are a clear indication that the people of Mpumalanga have collectively failed to protect the lives of persons with albinism, underlining the need for serious reflection on how we can better protect them”.

The Speaker emphasized that this democratic and people-centred Legislature, continue in its mission to take Parliament closer to the people catering for their diverse interests, needs and concerns. She further thanked the Select Committee on Public Participation charged with responsibility to preside over all Sectoral Parliaments and all stakeholders who participated in the planning towards this Sectoral Parliament. She

made a special appreciation to Albinism Society of South Africa for their generous donations and in particular the Executive Director- Ms Nomasonto Mazibuko for volunteering her time to contribute her ideas in this programme. She furthermore appreciated the presence of Advocate Faith Phala.

This seminar is convened under theme, "Celebrating 20 years of the Constitution and 20 years since the inception of the NCOP", which is an opportunity to make reflections on progress being made since the establishment of our democratic constitution in 1996.

Hon BT Shongwe assured the session that we despise all forms of discrimination, abusive behavior, persecution and marginalization based on class, race, gender and disability. As a country whose constitution is based on the protection of Human rights, we must work together to build a more caring society based on our shared value system underpinned by the spirit of human solidarity "ubuntu".

This seminar is therefore charged with the responsibility to discuss, share experiences, transfer knowledge and inspire our struggle for self-determination. The unfortunate reports of persecutions based on beliefs that certain body parts of people with albinism have supernatural powers, is a myth and must be eliminated. These superstitions are perpetuated by some amongst us in our communities and should be defeated.

It therefore starts with increasing awareness amongst our people, appreciating that this condition is misunderstood, that the physical appearance of these persons is still often subject to erroneous beliefs which foster exclusion.

7.2. CLR T KHOZA, EXECUTIVE MAYOR OF NKOMAZI LOCAL MUNICIPALITY

Executive Mayor expressed gratitude to Hon BT Shongwe for inviting them and for this remarkable day. She remarked that Mpumalanga Legislature is the first Legislature out of nine Provinces to host Parliament for People with Albinism and furthermore invited other Legislatures to learn from Mpumalanga. She encouraged all Municipalities to create a data base for people with albinism in their constituencies.

In her address she made it clear that this event was not for campaigning for any political party but representing the government and to show that they care for the people of Mpumalanga. She shared her experiences that Nkomazi municipality have a data base and they do public education for the People with Albinism. She indicated that they meet with traditional healers to dispel the myth that says body parts of people with albinism can cure many diseases and give luck to a person. She appealed that we love one another since we are all God's creation.

7.3. ADV FAITH PHALA

She alerted the session, "The United Nations established June 13th as International Albinism Awareness Day and this important day gives us the opportunity to raise awareness on albinism and strongly criticise all forms of violence, discrimination and exploitation against persons with albinism taking place in South Africa and many other African counties. Albinism is a genetically inherited condition that prevents the body from producing melanin, the pigment that colours skin, hair and eyes.

People with albinism have disabilities, in particular at risk of skin cancer and being short-sighted and they are also ordinary people, like you and I. Many people with albinism continue to live in object poverty and in fear of being attacked, abducted, or killed and the graves of the deceased are also exhumed. Some no longer dare to go outside, and children with albinism have stopped attending school many persons with albinism limit their movements.

Families of persons with albinism, are marginalised, and often driven from poverty into dire straits. Discrimination exists in the family, community, including in education and health services, particularly the lack of available and affordable skin cancer prevention measures, and is a need of urgent attention. The majority of attacks are against women and children who are particularly vulnerable, and face multiple and intersecting forms of discrimination. Addressing this systematically, through a multi sectoral approach is crucial to ending violence and discrimination against persons with albinism.

Prevention of attacks is critical, including raising awareness to confront the erroneous myths surrounding albinism, aimed at bringing about behavioural change, in line with the Government's response plan on attacks against persons. The need for skin care interventions, as there is evidence that people with albinism die disproportionately from skin cancer at an early age. Issues of skin cancer, poor vision and provide access to health services for persons with albinism and much more needs to be done. Improved data on persons with albinism is also important to ensure that people with albinism are not left behind in Mpumalanga Province.

Mpumalanga Legislature as Law making state organ must fight for people with Albinism and has a moral obligation to stand up for the human rights. In this regard, we all need to do more. The campaign to protect persons with albinism must continue if we are to witness zero attacks against persons with albinism. Let us all intensify efforts to protect persons with albinism. Together, we can make a real difference, above all ensuring that people with albinism are at the forefront of all interventions. People should know that Albinism is a disability because you can't function normally".

7.4. Ms N MAZIBUKO, EXECUTIVE DIRECTOR ALBINISM SOCIETY OF SOUTH AFRICA

She eloquently walked the session through policy shifts in the sector and warned, "Although much has been done by government in recognising the rights of persons with Disabilities, there is not much which has been done in recognition of the rights of Persons with Albinism. Persons with Albinism continue to experience social discrimination due to their physical appearance.

The office of the United Nations High Commissioner for the Human Rights published its Preliminary Report on the situation of Persons with Albinism in compliance with Resolution 125 "attacks and discrimination against persons with albinism". It was re-affirmed by the Universal Declaration of Human Rights and recalling relevant international human rights treaties, including the International Covenant on civil and Political Rights, the International Covenant of Economic, Social and Cultural Rights, the convention on the Rights of the Child and Convention on the Rights of Persons with

Disabilities. In reinforcing the United Commission on Human Rights, June 13 was declared as the International Awareness Day on Albinism.

In South Africa, a trend of human trafficking of young women and children with albinism has emerged. Persons with albinism are being used for muti purposes in the name of culture. There are two deaths that are reported from KZN both victims were young in their twenties.

Persons with Albinism are therefore calling upon government to:

- Ensure that June 13 to be included and observed in the National Calendar.
- Initiate legal action, public condemnation against perpetrators of these attacks
- Provide temporal shelters for Persons with Albinism under threats of attacks
- Provide free assessment and provision of sunscreens for prevention of skin cancer amongst persons with albinism
- Take all necessary measures to ensure effective protection of Persons with Albinism and their families.
- Provide adequate funding for awareness raising campaigns on Albinism.
- Provide employment and provision of assistive devices in the workplace for persons with albinism.
- Encourage and allow learners with albinism to be allocated large print textbooks and learning material.
- Provide reasonable accommodation in education, in giving extra time during tests and examinations.
- Give opportunity to be trained and given a chance in the open labour market.

The Albinism Society of South Africa is proud to announce that Persons with Albinism are getting qualifications; they are climbing the ladder of success. In the arts will see young persons as artists, as models, as this encouraging the younger generation.

In conclusion she thank the Mpumalanga Legislature for leading in South Africa to affirm and celebrate June 13 with them.

As people with albinism we know that Mpumalanga Province care and love us .Ms N Mazibuko promise the speaker of Mpumalanga Hon BT Shongwe that all people with Albinism will go back to school and go to universities and requested the Legislature to lead by example by hiring them when they come back from tertiary .

8. DELIBERATIONS WITH THE PUBLIC

Plenary raised the following issues for consideration by the Legislature:

- It was requested that whenever State Institutions have events for people with albinism, a person with albinism should be identified to provide leadership on such issues. This includes that local coordinators should be persons who understand Albinism.
- There is a need for a formal structure in the province to advance issues of people with albinism.
- People with albinism do not benefit from the Social Assistance grants as they were told they are not disabled. There is a plea to the Legislature to have a legislation that will allow people with albinism to be provided grant without any difficulties.
- A plea was made to the Legislature to engage with the Department of Labour in order to check organisations that claim to be looking for jobs for people living with albinism. Especially the one in KwaMhlanga that is called (Siyakha) because those structures are not serving the interest of the People with Albinism they are enriching themselves
- The Department of Health have trained people who are dealing with ("Human Genetics) but unfortunately they come from other Provinces, they resign and go back to their original provinces while their services are crucial. A plea is made to the Department of Health to recruit local to avoid this high turn-over of these specialists and disservice.

- A plea on age limit in terms of learnerships is made that it could be increased to accommodate older persons especially those who are disabled.
- The Department of Sport, Culture and Recreation is requested to have sporting activities that will accommodate people with albinism.
- The Department of Health should make sunscreens easily available for people with albinism as it is very expensive.
- The Department of Human Settlement should consider the needs of people with albinism when they subsidy build houses since most people with albinism are partially blind.
- The Department of Education should have more awareness workshops especially in schools where there are learners who are with albinism so that educators and other learners will know how to deal with them.
- The Legislature should not only spearhead a public awareness campaign for public servants, workshop them on conditions of people with albinism.
- The Department of Education should have a quota of bursaries set aside for people living with albinism.

8. FINDINGS

The Committee, after careful deliberations, made the following findings:

- Albinism Awareness day is not elevated in our calendar like human rights day and workers' day. There is a need for adequate funding for awareness raising campaigns on Albinism.
- People with albinism are not allowed to access social grants on the basis of albinism, instead they are required to prove extra disability.
- People with albinism need sunscreen to protect themselves against skin cancer.
- The educators don't understand the needs of children or people with albinism.
- Most people with albinism are short sighted, they can't read textbook that are written in small font.

- People with albinism need to be given reasonable accommodation in education, through extra time during tests and examinations.
- Most people with albinism need sunglasses to function normally in society.

9. RECOMMENDATION

In view of the findings above, the Committee therefore makes the following recommendations:

- The Department of Social Development must develop an Albinism Awareness Campaign to be run throughout the next financial year. This must sensitize society around matters of albinism, the myths and inherent discrimination.
- The Department of Social Development must spearhead policy shift that acknowledges albinism as a disability thus assist people with albinism with social grants.
- The Department of Social Development must create a database of people with albinism, and then give them an allocation of sunscreens per month.
- The Department of Education must conduct workshop for educators to alert them to stigma, unfairness and disabilities associated with albinism so that they assist learners with albinism accordingly.
- The Department of Education must provide text books with larger font (or reasonable access to electronic text books) to learners with albinism.
- The Department of Education must spearhead policy shift to accommodate learners with albinism. The policy must review possibilities of allocating learners with albinism extra time during tests and exams.
- The Department of Health must provide short sighted people with albinism with glasses, so that they can be access education.

10. CONCLUSION

On behalf of the Select Committee, the Chairperson wishes to thank all the Honourable Members of the Legislature and all role players who contributed in the preparations towards the successful hosting of the 2017 Parliament for People with Albinism.

This Committee report on the 2017 Parliament for People with Albinism is hereby tabled to the House with a request to adopt it with the recommendations for implementation by the respective Departments. A progress report must be tabled to the Committee by no later than 30 October 2017.



**HON JL NGHONDZWENI
CHAIRPERSON: SELECT COMMITTEE ON
PUBLIC PARTICIPATION, PETITIONS AND MEMBERS'
LEGISLATIVE PROPOSALS**

06-09-2017

DATE