



EPILEPSY AFRICA NEWS

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A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)



Image: Alliance for Rights – Africa Towards Disability Inclusion (ARADI) Southern Africa Regional Workshop held in Mauritius. AREC Vice-Chairperson Mr Youssouf Noormamode and Secretary Ms Betty Nsachilwa attended the workshop. EDYCS, our chapter in Mauritius organised the workshop. See report inside by Betty. Mr. Youssouf Noormamode is also the Vice Chair of Africa Disability Alliance (ADA).

This special issue focuses on the Alliance for Rights – Africa Towards Disability Inclusion (ARADI) Southern Africa Regional Workshop

About this newsletter: Editorial team: Jacob Mugumbate; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Monthly **Distribution:** Email and other social media. **Email contributions to:** ibeafrika@gmail.com. Enjoy your reading!

How to join us:

WhatsApp group for people with epilepsy and significant others: +260977789042, group for professionals interested in epilepsy: +260977789042. Epilepsy Africa **Facebook** group: <https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts> **Twitter:** [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica). **Email list:** We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrika@gmail.com.

Chairperson & Editor's message

This is the 14th issue of Epilepsy Africa newsletter. In this report you will find a detailed report about the human rights workshop held in Mauritius. The report was prepared by Ms Nsachilwa, our Secretary who attended the workshop. I wish to take this opportunity to encourage you to take opportunities being announced by the IBE, including promising strategies, golden awards and social accomplishment awards. I also want to encourage you to begin to prepare for International Epilepsy Day next year. We need to do more awareness and advocacy. In the next issue, we will announce countries that are going to implement advocacy projects. Please contribute to this newsletter by sending an email to ibeafrika@gmail.com. Enjoy your reading. *Jacob*.



Alliance for Rights – Africa Towards Disability Inclusion (ARADI) Southern Africa Regional Workshop

Held from 26th to 29th August, 2018 held at Gold Crest Hotel in Quatre Bornes, Mauritius

Report by Ms. Betty Barbara Nsachilwa, IBE Africa Regional Executive Committee and Epilepsy Association of Zambia, 2018

1.0 Preamble:

Following a directive by the Africa Union Social Policy Framework for Africa and continental Plan of Action on the African Decade of Persons with Disabilities (2010-2019) to the African Commission on Human And People's Rights (ACHPR) to "Elaborate and adopt an additional Protocol to the African Charter on Human and People's Rights relating to the rights of persons with disabilities", a **Protocol** on the Rights of Persons



with Disabilities was formulated in conjunction with Africa Disabilities Alliance (ADA) who provided the resources, expertise, capacity, research evidence, diplomacy and international influence that guided the development of the Protocol.

It was then decided to approach the continent of Africa through regional workshops. As a result, Africa Disability Alliance (ADA) through Edycs Epilepsy Group as a sub grantee of the Alliance for Rights Africa Towards Disability Inclusion organized a workshop in

Mauritius from 27th to 29th September 2018 for the Southern Region countries with funding from European Union and CBM. The following countries were present at the workshop: Ethiopia, Comoros, Seychelles, Madagascar, Malawi, Rodrigues, South Africa, Zambia and Mauritius, the hosting nation. There were seven (7) foreign participants and thirty-one (31) local representatives from Ministries, DPOs, Parastatals, NGOs, SEN Schools and Corporates of Mauritius. I attended the workshop by virtue of representing the IBE Africa Regional Executive Committee.

2.0 INTRODUCTION, KEY NOTE ADDRESS AND PRESENTATIONS - 27TH AUGUST, 2018



The Programme Moderator - **Deputy President, Edycs Epilepsy Group, Mr. Paramasiva Chengan** gave the introductory remarks and welcomed the regional and local delegates. Mr. Chengan said the workshop was important in order to push the Protocol on disability to the Government and sensitization was already in place. Delegates were urged to act as ambassadors to see that the Protocol is ratified in Southern Africa.

2.1 Official Opening

The official opening session had four main speakers during the official opening.

The President of Edycs Epilepsy Group of Mauritius - **Mr. Youssouf Noormamode, (who is the vice chair of ADA and also Vice Chair of IBE Africa regional committee)** informed all that the Workshop was essentially organized to put disability in the limelight as most Heads of States in Africa have already recognized that disability should be considered as a priority. It was also revealed that

84,000,000 people with disabilities in Africa face discrimination and stigma, therefore, pursuing for the rights of persons with disabilities was unquestionable.

Thereafter, the Chairperson Africa Disability Alliance – Ms. Grace Enock Massah spoke



on Africa Disability Alliance, followed by the Africa Union Commission from Legal Counsel Department - Mr. Lefhoko Kesamang. Most importantly was the Keynote Address by the Deputy Speaker of the National Assembly of Mauritius, **Hon. Mr. Mahendranuth Sharma Hurreeram**, as the Chief Guest. The Chief Guest gave a Keynote Address emphasizing the ratification of the Protocol on Disability by African States. The Guest Speaker, like all previous speakers, was appalled to learn of incidences of discrimination and stigma faced by persons with disabilities in this time and age, citing one incident of

throwing a child with Down's syndrome into a river because it is believed that such children belong to the river and are thus thrown into the river. The Hon. Deputy Speaker urged participants to have a fruitful workshop. The Hon. Deputy Speaker assured the AUC representative, Mr. Kesamang that the Government of Mauritius was already seriously looking into issues of disability. Thus, creating an equal society to the inclusion of people,



implementing adequate measures and facilities to accommodate equality of life for people with disabilities such as building control measures for accessibility and gender equality. Also that the relevant Ministry was already working on the Disability Bill. The Government also recognizes the existence and hard work of the NGOs for people with disabilities and was already giving the needed support to such NGOs.

2.2 Africa Disability Protocol Presentation:

The delegates were informed of the review and update on the Africa Disability Protocol process by the **Chairperson of Africa Disability Alliance (ADA), Ms. Grace E. Massah**. Ms. Massah explained that the AU disability Architecture (AUDA) has three (3)



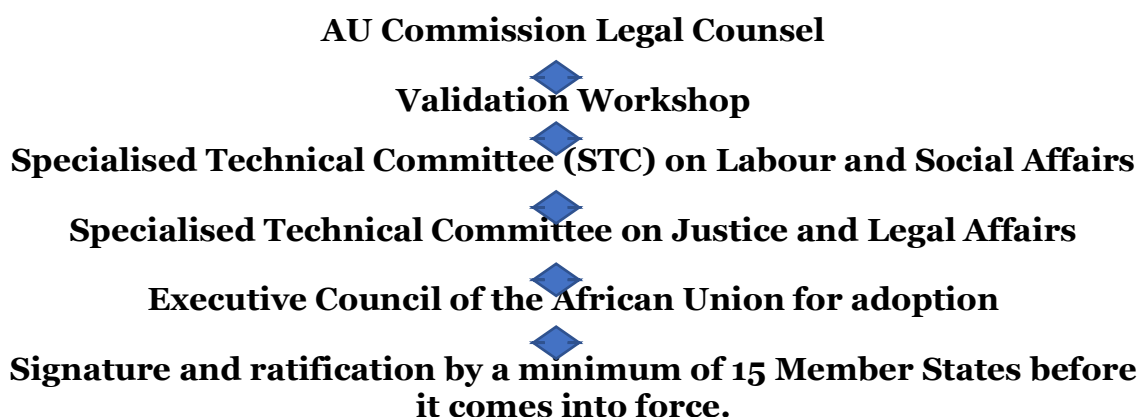
parts i.e. (a) The legal component – the Draft Protocol to the African Charter on Human Rights on the Rights of Persons with Disabilities (The Protocol); (b) The programmatic component – a Continental Plan of Action for the African Decade of Persons with Disabilities (2010-2019); and, (c) The Institutional component, currently named the African Union Disability Institute (AUDI). We were also informed that the Protocol addresses the

following:

- the fundamentality of rights of persons with disabilities,
- the obligations of State Parties, equality and non-discrimination,
- affirmation of the right to life, including particular focus on persons whose disabilities make them particularly vulnerable to lose their lives e.g. persons with albinism and those with intellectual or psychosocial disabilities,
- equality before the law, and
- the right education, with focus on inclusive education – that programmes be put in place on a progressive basis to ensure every child with disability receives an inclusive education, etc.

Path to the Adoption of the Draft Protocol:

Adopted at the 19th Extra-Ordinary Session of the African Commission on Human and Peoples' Rights, February 2016, in the Islamic Republic of The Gambia. The adopted Draft submitted to the AUC as follows:



2.3 Other speakers on the first day, were **Ms. Aida Sarr - Director Communication and Public Relations (ADA)**, who explained the activities of ADA and objectives of the Regional Training Sessions which were aimed at sharing country experiences and good practices in advocacy campaigning as well as creating networking and strengthening collaboration between disabled people's organisations (DPOs) and other stakeholders. Ms. Sarr assured the audience that ADA shall support the AU organs and facilitate among other things in Development of toolkits and manuals on disability mainstreaming and accessibility of the



ACHPR/AUC and the Pan African Parliament (PAP) while providing technical support and advice for conducive environment for all. The following speaker, **Mr. Sivaramen Subbarayan, Legal Affairs Director, University of Mauritius (UOM)** who gave an inspiring topic on **Disability in Africa** and encouraged all to consider appealing against decisions that do not favour the laid down procedures or policies,

and Mr. Chet Bundhoo – Director, Disability Consulting Services Limited on Disability Scope and Challenges in the Republic of Mauritius, who advised that ability matters and that there was need to move from a medical model to a social model or human rights. Encouraged that Disability Persons Organisations should be led by persons with disability thus enforcing their rights and avoiding misrepresentation.

2.4 Explanation on the Protocol and why it is important:

Mr. Lefhoko Kesamang, Africa Union Commission, spoke again on A Call to the Signing and Ratification of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities.

Mr. Kesamang gave information on benefits of the *Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa* that it:



- Would provide the first comprehensive African normative basis for ensuring the rights of persons with disabilities as full human beings with inherent dignity and not as mere objects;
- Is informed by the social model of disability rather than the charity and medical models of disability which have guided policy and law-making across much of Africa;
- Recognizes the important standards set by the Convention on the Rights of Persons with Disabilities (CRPD); and it does not undermine any of those standards.

AU Disability Protocol

- Introduces further normative standards of particular relevance to Africa to ensure full and effective protection and promotion of the rights of persons with disabilities in Africa;
- Establishes the content and institutional basis to enable persons with disabilities to seek redress wherever their rights are violated;

- Will offer political and diplomatic possibilities at the Continental level for rallying advocacy and action to ensure the rights of persons with disabilities in Africa

Why ratify?

The participants were informed that it was important to ratify because Africa has its specifics to consider, especially on discrimination and stigma.

Your Role in the Ratification

1. Lobbying Political Leaders – National Level
2. Lobbying Political Leadership: Regional Level
3. Lobbying Political Leaders: Continental Level
4. Empower Persons With Disabilities to speak for themselves
5. Disability Studies at Tertiary Level
6. Be a Disability Advocate
7. Be a researcher in disability rights and development: Data Collection
8. Disability Awareness, Inclusion and Mainstreaming: Trainings; Workshops; Seminars; TV and Radio; Newspaper Articles/Columns; Volunteering;
9. Be the Change you Want to See: ‘Change Agent’
10. Be an Activist: Politically, Developmentally etc.
11. Analysis of the Development of Policy and Legal Instruments.

Finally, Mr. Kesamang also urged the participants to give the needed support to the ratification of the Protocol on the Rights of Elder Persons. **As alluded to earlier, for the Protocol to be in force there is need for 15 Countries to sign and ratify the same.**

2.5 Group Work:

The day ended with group work to discuss two issues: **What role persons with disabilities, DPOs, NGOs and Other institutions should play in lobbying government towards the ratification of the Africa Disability Protocol?** and **What are the underlying advocacy strategies and time frame?**

There were four groups and each group presented their discussions on the next day. The teams understood their role of having knowledge about the Protocol before asking others for support and also laid down strategies on how to advocate in a specified period time.

3.0 KEYNOTE ADDRESS AND PRESENTATIONS ON 28TH AUGUST, 2018:

3.1 Keynote Address: The AUC/EU Representative on Human Rights – His Excellency, Commissioner YKJ Yeung Sik Yuen spoke on “The road ahead to the Ratification of the ADP”.



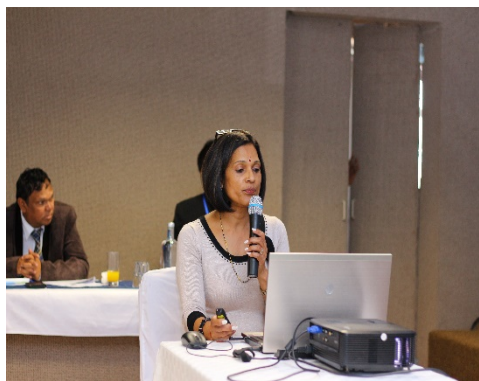
H.E. Commissioner Yuen noted that organizing fora like the ARADI Workshop to persuade Governments to take matter of ratifying the Protocol was a well thought of idea. His Excellency urged all present **“to drink the cup to the last drop”**.

His Excellency the Commissioner also commended the AUC Representative, Mr. Kesamang, for his tireless effort to ensure that the message on the Africa Disability Protocol was spread and supported. Civil servants were

also urged to request for expeditious execution.

3.2 Presentations by Regional Delegates:

Each participant presented on their country's disability situation and gave the current situation regarding the rights of people with disabilities. It was worth noting that some countries though not having ratified the protocol, the collaboration between Disabled Persons Organizations, Civil Society Organizations and the Governmental Ministries was well ahead of the some steps to be taken to uphold the Protocol.



Mrs. Ancella Ramjas – Down Syndrome South Africa



Ms. Betty B. Nsachilwa – IBE Africa/EAZ



**Mrs. Razaka Ralphine Manatenasoa – Madagascar
Réseau National des Femmes Handicapées de Madagascar**



Mr. Raymond Damou – Caritas Seychelles



**Mr. Ibrahima Ahamada – Comoros
National Director – Solidarity and Social Protection**



**Mr. Jean François Begué – Rodrigues Help to
Grow SEN School.**

3.3 Support to the Mauritius Team:

After the presentations, all participants were moved to support Mauritius by way of Adopting and signing the Mauritius Declaration to the Call for Ratification of the Protocol. The Declaration would then be presented to the relevant Governmental Officials as will be shown latter in this report.

3.4 Closing Ceremony:

The ARADI Workshop was officially closed by the **Chief Guest – Honourable Ravi Rutnah, Government Deputy Chief Whip**, who thanked the participants for their commitment to pursuing the implementation of the ADP and urged all present to support Mauritius to be the first to ratify the Protocol. The Chief Guest later presented certificates and awards of recognition to participants. Like all regional delegates, IBE Africa Regional Executive Committee received an Advocacy and Disability Rights Promotion Award and a book on International Disability Law.



4.0 OFFICIAL VISITS TO RELEVANT AUTHORITIES IN MAURITIUS - 29TH AUGUST, 2018

Edycs the host of the project organized visits to Governmental Authorities in order to support their course of ratification by the Mauritian government

4.1 A number of courtesy calls were organized prior to the Workshop to present the signed Mauritius Declaration to Call for Ratification of the Protocol to relevant Authorities. Consequently, some of the regional delegates accompanied the



Edycs Epilepsy Group President, Mr. Youssouf Noormamode firstly to visit the Lord Mayor of Port Louis, Mr. Daniel Eric Clive Laurent at the Council Hall, Municipality of Port Louis.

The Lord Mayor of Port Louis, Mr. Daniel Eric Clive Laurent, in the middle - forth from right

4.2 The second courtesy call and meeting was with the Hon. Marie Joseph Noël Etienne Ghislain Sinatambou, Minister of Social Security, National Solidarity and Environment and Sustainable Development. However, the Hon. Minister was busy and delegated the Permanent Secretary to attend to the delegation. The team had a fruitful meeting with Permanent Secretary and some Senior Officials, who also alluded to Mauritius already having in place most of the steps leading to the ratification of the Protocol. Citing an example of compulsory rule on infrastructure that all newly constructed buildings to ensure easy accessibility for all, hence the construction of ramps at all buildings.



4.3 The third visit was on the Attorney General who represented the Hon. Minister of Justice. The Attorney General accepted the petition and also presented a copy of the Mauritius Constitution to all present.

4.4 The next visit and meeting was with NGO Trust Fund under Ministry of Social Security, national Solidarity and Environment and Sustainable Development.



4.5 The final courtesy call was on the Mauritius Council of Social Services (MACOSS), an umbrella organisation for all NGOs in the Republic of Mauritius.

RECOMMENDATION:

The onus lies on all IBE African Chapters, to see how we could be advocates for the Africa Disability Protocol. As mentioned earlier, the Protocol will constitute an important component of the African Union Disability Architecture and should, therefore, be treated as a matter of urgency to provide the extra force to realize the rights and provide the services to address the needs of persons with disabilities. It is advisable to consult the stakeholders who have been pursuing the issue on disability with the governmental authorities and find out how far they have gone to ensure the country's ratification of the Protocol. Access the Protocol on the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa through this link: http://www.achpr.org/files/news/2016/04/d216/disability_protocol.pdf

CONCLUSION

The regional delegates were treated to a warm reception at the EDYCS Epilepsy Health Service Centre giving delegates an opportunity to learn just how EDYCS Epilepsy Group is organized. The tour of the offices and revelation of activities at the Centre showed the commitment of the organization. The EDYCS Epilepsy Health Service Centre and the SEN School are run transparently, efficiently and effectively with focused leadership. A good example to emulate as Epilepsy Associations in Africa. An Association must be well founded, having open networking channels with other stakeholders and relevant Authorities in the country. An Association should be run by a team and not as a personalized organization which makes it difficult for transition if the personal attachments are lost at some point. To the organizers of the Workshop, I express gratitude for the great opportunity offered to attend such an informative Workshop. Keep up with the same spirit of inspiring others to be a force for good and a **‘voice for the voiceless’**.

Please contribute to the newsletter

We are calling for chapters, their groups and members to contribute to the newsletter. You could share this with us: Stories of members showing how they are overcoming epilepsy, your local newsletter, Questions and Photographs.

We are on social media, join us today

You are encouraged to join these social media groups, and participate, follow, like posts, and comment regularly:

- WhatsApp Group for people with epilepsy and significant others: +260977789042
- WhatsApp Group for professionals interested in epilepsy: +260977789042
- Epilepsy Africa Facebook group: <https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts>
- Email list: We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrika@gmail.com.
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

In the next issues of the newsletter, we will talk about countries that will host advocacy projects, our regional website and other issues.



International Epilepsy Day

Monday, 11th February 2019
Start Preparing Now! See poster on next page.



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VIDEO COMPETITION



DEADLINE: 14TH DECEMBER 2018



International
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AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!

The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US\$500 and five Runners' Up prizes of US\$100.

CATEGORY ONE:

My Personal Story

People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO:

Educational Video

Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

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