IBE International Bureau for Epilepsy

AFRICA REGION

Report on the IBE Africa 21 State Epilepsy Health Laws Mapping Exercise

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Executive Summary

WHA Resolutions 68.20 and 73.10 implore all UN Member States to address epilepsy as a public health imperative by developing and implementing global and national action plans on epilepsy. Further, UN Member States are encouraged to reinforce human rights based policies and laws for people with epilepsy at national and international levels through novel strategies. However, on the African continent, very little progress has been made in this regard. In fact, despite several African States committing to international treaties concerning the universal right to health and the protection of the rights of persons with specific health needs, there is still a dearth of unambiguous national policies and laws as well as accompanying monitoring and enforcement mechanisms.

This report reflects on how health laws may be used to strengthen the prioritisation of epilepsy in resource-restricted settings, specifically, in the African context. Health laws are defined by WHO as the area of law concerned with the health of individuals and populations, the provision of healthcare and the operation of the healthcare system. Through a health laws mapping exercise, the state of advancement and implementation of resolutions concerning epilepsy can be monitored. Doing so will add value to anticipated evaluation mechanisms stemming from WHA Resolution 73.10 which calls for a Global Action Plan on Epilepsy (and other Neurological Disorders). This will further provide evidence-based research for epilepsy advocacy strategies on matters concerning health legislation and national policies.

By and large, the existing data on health laws in Africa is not easily accessible, nor regularly updated on public platforms and is not comparable between States. In the context of making epilepsy a priority in Africa, the status quo reduces the capacity of key interlocutors to develop national policies, plans and evidence-based responses on epilepsy. This further hinders efforts to monitor and report on progress made towards implementing WHA Resolutions 68.20 and 73.10.

Twenty-one African States are analysed in this report through their international commitments and the hierarchy of their national laws as they relate to epilepsy. These are: Angola, Botswana, Cameroon, Comoros, the DRC, Eswatini, Kenya, Lesotho, Madagascar, Malawi, Mauritius, Mozambique, Namibia, Nigeria, Rwanda, Seychelles, Sierra Leone, South Africa, Tanzania, Zambia and Zimbabwe.

The international and regional treaties of particular relevance to this study are: the ICCPR, ICESCR, CEDAW, CRC, CRPD, ACHPR, the AU Disability Protocol (not yet in force), the Maputo Protocol, the African Children's Charter and the African Youth Charter. None of the twenty-one States studied in this report have ratified all ten instruments however, Angola, Rwanda and South Africa have ratified nine of the ten instruments and have, at least, signed the outstanding one – thereby indicating intention to ratify the instrument at a later stage. The concepts of signing and ratifying an international treaty are discussed in Section B of this report. Nonetheless, domestic implementation of international treaties remains a critical challenge in the States studied.

Summary table of ratifications (international and regional instruments)

	ICCPR	ICESCR	CEDAW	CRC	CRPD	ACHPR	AU Disability Protocol	Maputo Protocol	African Children's Charter	African Youth Charter
Angola	X	X	X	X	X	X	S	X	X	X
Botswana	X	-	X	X	-	X	-	-	X	-
Cameroon	X	X	X	X	S	X	S	X	X	X
Comoros	S	S	X	X	X	X	-	X	X	S
DRC	X	X	X	X	X	X	-	X	S	S
Eswatini	X	X	X	X	X	X	-	X	X	X
Kenya	X	X	X	X	X	X	-	X	X	X
Lesotho	X	X	X	X	X	X	-	X	X	X
Madagascar	X	X	X	X	X	X	-	S	X	S
Malawi	X	X	X	X	X	X	-	X	X	X
Mauritius	X	X	X	X	X	X	-	X	X	X
Mozambique	X	-	X	X	X	X	-	X	X	X
Namibia	X	X	X	X	X	X	-	X	X	X
Nigeria	X	X	X	X	X	X	-	X	X	X
Rwanda	X	X	X	X	X	X	S	X*	X	X
Seychelles	X	X	X	X	X	X	-	X	X	X
Sierra Leone	X	X	X	X	X	X	-	X	X	S
South Africa	X	X	X	X	X	X	S	X	X	X
Tanzania	X	X	X	X	X	X	-	X	X	X
Zambia	X	X	X	X	X	X	-	X	X	X
Zimbabwe	X	X	X	X	X	X	-	X	X	X

Key- S: Signed **X**: Ratified **X***: Ratified with reservations on the right to health

The African States studied have adopted, in a myriad of ways, a blanket approach towards covering epilepsy through non-communicable diseases (NCDs), mental health issues, disability health laws and related policies. But, the absence of specific national action plans and the non-recognition of epilepsy in so many key laws and strategies which expressly recognise other NCDs, mental conditions and are clear about the national concept of disability, adds to the challenges experienced by the millions of people with epilepsy on the continent. Several mental health instruments contain elements which diminish the legal capacity and rights of persons with mental health concerns. Archaic laws which still approach mental health concerns through the frame of legislation on "lunacy" were observed in two countries – namely, Nigeria and Sierra Leone. In Nigeria, although there is no official mention of epilepsy in health legislative texts or regulations, survey responses show that epilepsy is widely regarded as a mental health issue. As such, this common assumption renders persons with epilepsy potentially subject to the Nigerian Lunacy Ordinance of 1958 which deals with all mental illness from the point of "lunacy". This law is the only

instrument which tackles mental health issues at the federal state level.

The findings also indicate that in the countries studied, the implementation rates of general health laws and policies are low and this only pushes epilepsy, as a specific concern, lower on the agendas of legislators, policy makers and government officials, who were described in the survey responses as uninformed or untrained on epilepsy issues. In countries such as Angola and Botswana that have legislation and health policies addressing disabilities, mental health and NCDs, epilepsy is not at all mentioned, despite significant prevalence rates. It is therefore a common assumption that epilepsy in these countries is covered by the all-encompassing provisions relating to the health laws of persons with disabilities. Likewise, survey responses also highlighted how in many countries, in the absence of clear guidelines, persons with and affected by epilepsy are drawn to assume that the State considers epilepsy as a disability. Disability has multiple precise definitions in various settings with the common factors being physical and / or mental impairment. As such, persons with epilepsy who identify as having disabilities may seek social support from the State, where it is provided specifically for persons with disabilities. Such an approach is a challenge in countries like Cameroon where a disability threshold is implemented as a pre-requisite to obtain a disability card which then enables access to disability social services.

While it is anticipated that progress towards the development of a global action plan on epilepsy is imminent, it is questionable whether States that have not at their national level began to acknowledge epilepsy as a pressing health concern, could make significant and domestically translatable contributions to such global action plan. The negative outcome thereof being the risk that another international commitment on epilepsy fails to live up to the hopes of those affected.

Abbreviations

ACHPR	African Charter on Human and Peoples' Rights
AU	African Union
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women / Committee on the on the Elimination of all forms of Discrimination Against Women
CESCR	Committee on Economic, Social and Cultural Rights
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
HRC	Human Rights Committee on Civil and Political Rights
IBE	International Bureau for Epilepsy
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
NCD(s)	Non-Communicable Disease(s)
UDHR	Universal Declaration on Human Rights
UN	United Nations
ILC	International Law Commission
WHA	World Health Assembly
WHO	World Health Organisation

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This report would have been incomplete without the collaboration of the International Bureau for Epilepsy's African Regional Executive Committee as well as the contributions made by the following epilepsy support organisations which served as resource points and coordinators:

- ASLEK, DRC
- Community Development and Epilepsy Foundation, Cameroon
- EDYCS Epilepsy Group, Mauritius
- Epilepsy Association of Nigeria
- Epilepsy Association of Zambia
- Epilepsy Lesotho
- Epilepsy South Africa
- Epilepsy Support Association of Mozambique (AMAPE)
- Epilepsy Support Foundation, Zimbabwe
- Eswatini Epilepsy Organisation
- National Epilepsy Association of Malawi (NEAM)
- Young Epilepsy Botswana

A special note of gratitude extends to all the individuals who participated in the survey undertaken as part of this study.

Contents

Section A

1. Introduction

The International Bureau for Epilepsy estimates that 10 million people in Africa have epilepsy. Furthermore, statistics reveal that at least 80% of the population of people with epilepsy in Africa, do not receive the healthcare they require, owing to various reasons, including incapacity to assert and claim their rights thereto. WHA Resolutions 68.20 and 73.10 respectively implore all UN Member States to address epilepsy as a public health imperative by developing and implementing global and national action plans on epilepsy. Further, UN Member States are encouraged to reinforce human rights based policies and laws for people with epilepsy at national and international levels through novel strategies. However, on the African continent, very little progress has been made in this regard. In fact, despite several African States committing to international treaties concerning the universal right to health and the protection of the rights of persons with specific health needs, there is still a dearth of specific national policies and laws on epilepsy as well as accompanying monitoring and enforcement mechanisms. The present research reflects on how health laws may be used to strengthen the prioritisation of epilepsy in resource-restricted settings, specifically, in the African context. Through a health laws mapping exercise, we will be able to monitor the state of advancement and implementation of resolutions concerning epilepsy so that they do not continue to be reduced to empty declarations. Doing so will add value to anticipated evaluation mechanisms stemming from WHA Resolution 73.10 which calls for a Global Action Plan on Epilepsy (and other Neurological Disorders). This will further provide evidence-based research for epilepsy advocacy efforts on matters concerning health legislation and national policies. Twenty-one African States are studied in this research through their international commitments and the hierarchy of their national laws as they relate to epilepsy.

Generally, the existing data on African health laws is not easily accessible, nor regularly updated on public platforms and is not comparable between States. In the context of making epilepsy a priority in Africa, the status quo reduces the capacity of key interlocutors to develop national policies, plans and evidence-based responses on epilepsy. This further hinders efforts to monitor and report on progress made towards implementing WHA Resolutions 68.20 and 73.10. Findings indicate that in the countries studied, the implementation rates of general health laws and policies are low and this only pushes epilepsy, as a specific concern, lower on the agendas of legislators, policy makers and government officials, who were described in the survey responses as uninformed or untrained on epilepsy issues. In countries such as Botswana which has a specific clause on non-communicable diseases in its Public Health Act and has a fairly new Non-Communicable Diseases Strategy, epilepsy is not at all mentioned amongst other non-communicable diseases, despite significant prevalence rates. Moreover, as far as inter-sectoral collaboration is concerned, respondents in only two of the

[1] International Bureau for Epilepsy, "Advocate's Toolkit for Making Epilepsy a Priority in Africa" (2021) at 8.

[2] Ibid.

[3] Defined by WHO as the area of law concerned with the health of individuals and populations, the provision of healthcare and the operation of the healthcare system.

sixteen countries invited to participate in the survey informed that there is engagement between State and non-State stakeholders on epilepsy matters. These examples reveal how international commitments on epilepsy are not translating into domestic impact through the development of policies and plans.

2. Objectives

To support regional efforts, the African Chapter of the IBE has undertaken a number of initiatives geared towards improving advocacy for epilepsy issues in Africa. These efforts include the publication of an “Advocate’s Toolkit for Making Epilepsy a Priority in Africa” and a proposed training on strategic litigation, legal defence and advocacy.

As part of the aforementioned endeavours, this epilepsy health laws mapping exercise seeks to: identify the key provisions on epilepsy health laws in Africa; study the existing gaps in law and to define areas for strategic advocacy initiatives. The aim of this exercise is to support public health lawyers, policy analysts, epidemiologists, people with epilepsy and epilepsy organisations to strengthen national and regional policies and laws for persons with epilepsy.

The process of legal mapping reports the results of research which aims to determine what laws exist on a certain aspect and collect information. The information collected forms the basis of an analysis on the content of laws. In this manner, the effect of the law on various interest areas can be measured in order to identify loopholes, opportunities and further generate evidence-based activities in relation to the interest area. In the present context, a mapping of epilepsy health laws will build evidence for advocacy efforts which will support the prioritisation of epilepsy in national and international agendas as well as monitor the state of advancement and implementation of international resolutions on epilepsy.

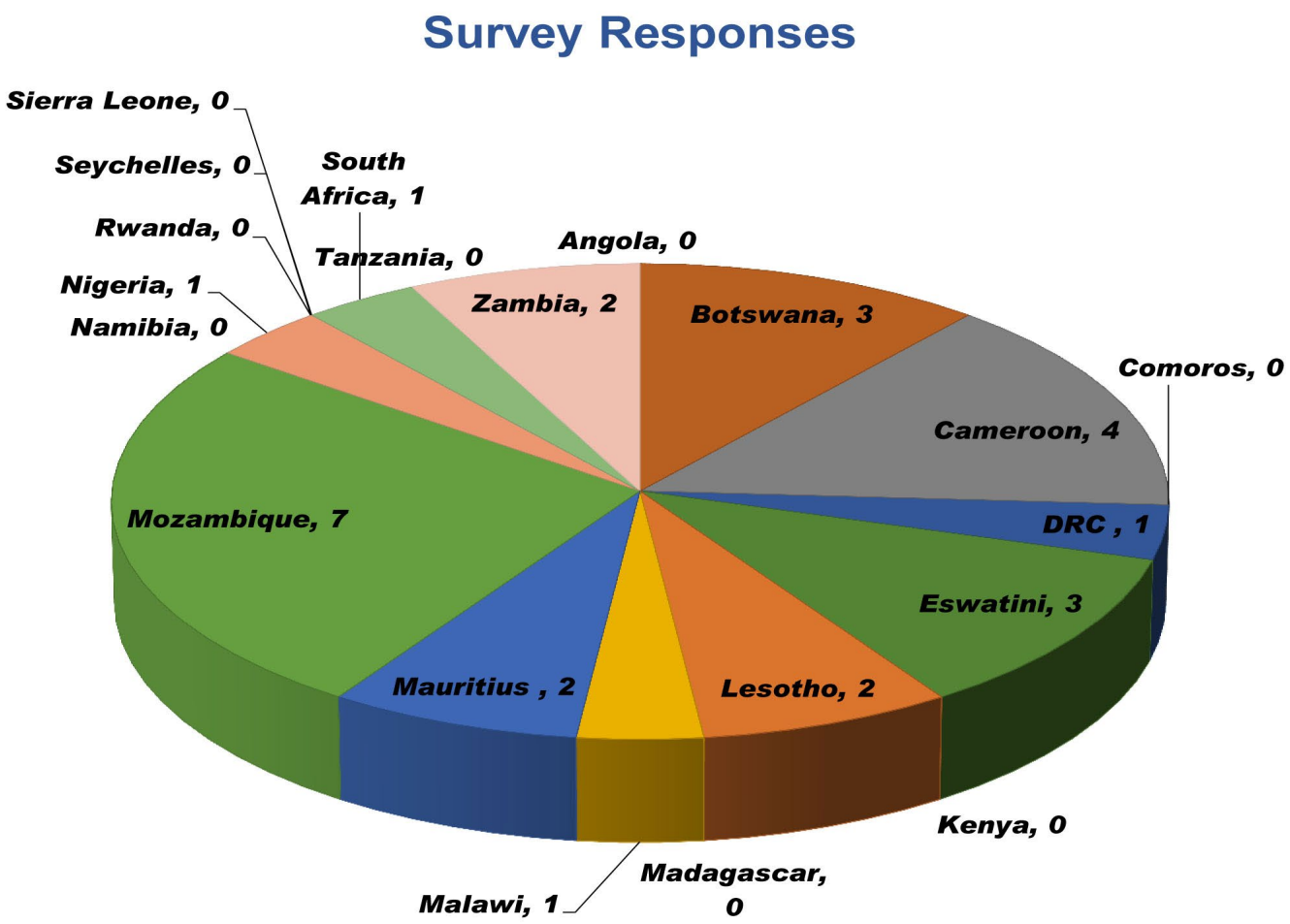
3. Methodology

A desk review of existing international and national policies, laws and other relevant information was systematically conducted together with key informant consultations and a survey involving various knowledgeable and / or affected participants in sixteen of the twenty-one countries under study.

The desk review included searches of national and non-State managed databases using key terms such as: “epilepsy”; “disability”; “disabled”; “public health”; “neurological”; “mental health”; “mental illness”; “brain health”; “seizures”; and “non-communicable diseases/NCDs”. Translations of the same terms were also used to search database in Francophone and Lusophone countries. All data in this report is presented in English with some legislative text titles also provided in their original languages. From the resources traced, a technical analysis of the laws which are of relevance to epilepsy was conducted, specifically as they related to matters of health law. Domestic laws, policies, strategies, and national guidelines were methodically evaluated using the most common

hierarchical framework of national instruments which ranks the Constitution as the most paramount, followed by other legislative texts and then public regulations and national policies, strategies and action plans.

The survey was conducted through an online data capturing form which prompted responses concerning the national context of health laws, the prioritisation of epilepsy in the country concerned as well as the obstacles encountered by persons with epilepsy towards enjoying their health rights. Sixteen out of the twenty-one countries studied were invited to participate in the survey. From this, a minimum of 48 individuals were expected to respond. Responses were received from twelve of these countries, namely: Botswana, Cameroon, the DRC, the Kingdom of Eswatini, the Kingdom of Lesotho, Malawi, Mauritius, Mozambique, Nigeria, South Africa, Zambia and Zimbabwe. A total of 28 individual responses were submitted.



[4] Angola, Botswana, Cameroon, Comoros, the DRC, Eswatini, Kenya, Lesotho, Madagascar, Malawi, Mauritius, Mozambique, Namibia, Nigeria, Rwanda, Seychelles, Sierra Leone, South Africa, Tanzania, Zambia and Zimbabwe.

4. Limitations

Whereas it is acknowledged that persons with epilepsy interact with and are impacted by the law in various ways, this study only looks at one specific field – health laws.

Moreover, this epilepsy health laws mapping exercise focuses solely on: Angola, Botswana, Cameroon, Comoros, DRC, Eswatini, Kenya, Lesotho, Madagascar, Malawi, Mauritius, Mozambique, Namibia, Nigeria, Rwanda, Seychelles, Sierra Leone, South Africa, Tanzania, Zambia and Zimbabwe. These selected countries represent only 21 of the 54 States on the continent.

It is further recognised that due to underdeveloped electronic data and archive management systems as well as poor monitoring and reporting mechanisms observed in many countries, there may be provisions of relevance to this study which have not been analysed in this report.

5. Summary of country analysis

By and large, the existing data on health laws in Africa is not easily accessible, nor regularly updated on public platforms and is not comparable between States. In the context of making epilepsy a priority in Africa, the status quo reduces the capacity of key interlocutors to develop national policies, plans and evidence-based responses on epilepsy. This further hinders efforts to monitor and report on progress made towards implementing WHA Resolutions 68.20 and 73.10.

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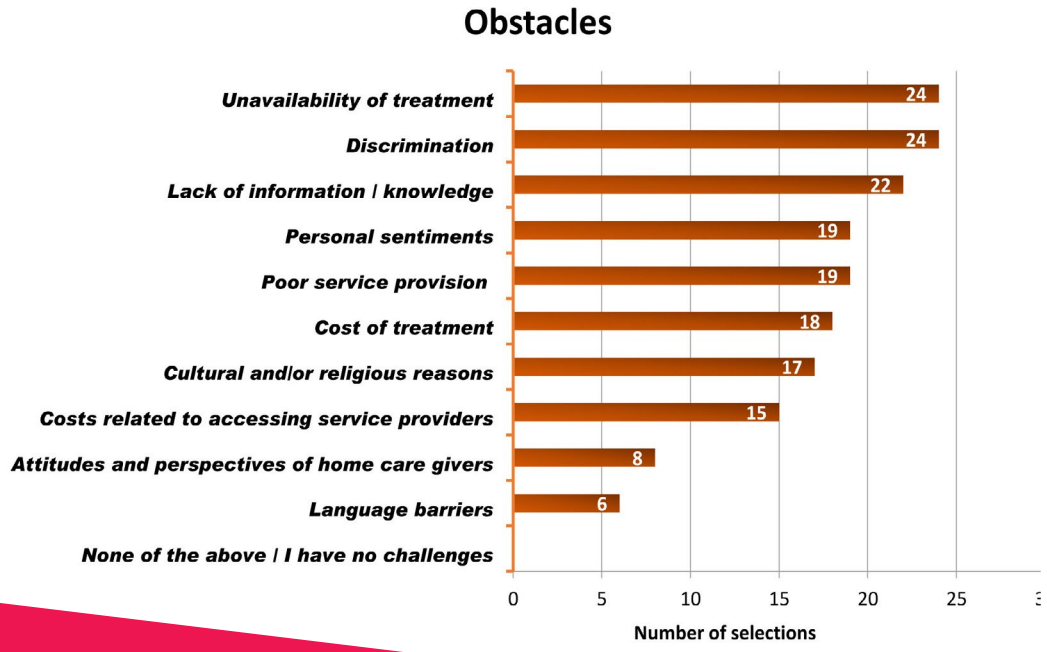
The African States studied have adopted, in a myriad of ways, a blanket approach towards covering epilepsy through non-communicable diseases (NCDs), mental health issues, disability health laws and related policies. But, the absence of specific national action plans and the non-recognition of epilepsy in so many key laws and strategies which expressly recognise other NCDs, mental conditions and are clear about the national concept of disability, adds to the challenges experienced by the millions of people with epilepsy on the continent.

Several mental health instruments contain elements which diminish the legal capacity and rights of persons with mental health concerns. Archaic laws which still approach mental health

concerns through the frame of legislation on "lunacy" were observed in two countries – namely, Nigeria and Sierra Leone. In Nigeria, although there is no official mention of epilepsy in health legislative texts or regulations, survey responses show that epilepsy is widely regarded as a mental health issue. As such, this common assumption renders persons with epilepsy potentially subject to the Nigerian Lunacy Ordinance of 1958 which deals with all mental illness from the point of "lunacy". This law is the only instrument which tackles mental health issues at the federal state level.

The findings also indicate that in the countries studied, the implementation rates of general health laws and policies are low and this only pushes epilepsy, as a specific concern, lower on the agendas of legislators, policy makers and government officials, who were described in the survey responses as uninformed or untrained on epilepsy issues. In countries such as Angola and Botswana that have legislation and health policies addressing disabilities, mental health and NCDs, epilepsy is not at all mentioned, despite significant prevalence rates. It is therefore a common assumption that epilepsy in these countries is covered by the all-encompassing provisions relating to the health laws of persons with disabilities. Likewise, survey responses also highlighted how in many countries, in the absence of clear guidelines, persons with and affected by epilepsy are drawn to assume that the State considers epilepsy as a disability. Disability has multiple precise definitions in various settings with the common factors being physical and / or mental impairment. As such, persons with epilepsy who identify as having disabilities may seek social support from the State, where it is provided specifically for persons with disabilities. Such an approach is a challenge in countries like Cameroon where a disability threshold is implemented as a pre-requisite to obtain a disability card which then enables access to disability social services.

Regarding the obstacles encountered by persons with epilepsy towards enjoying their health rights, the aspects reflected below were indicated as the most grievous and common in the survey participating countries.



[5] The provisions of Decree No 2018/6233 fixing the procedures of Law N° 2010 / 002 of 13 April 2010 on the protection and promotion of persons with disabilities apply to persons with disabilities holding a National Disability Card and justifying a Permanent Potential Incapacity Rate (IPP) of at least fifty percent (50%).

Section B

6. Terminology and the classification of epilepsy

Epilepsy in various settings is considered as either: a disability, a mental health disorder/ illness, a chronic condition, a neurological condition/disorder or a non-communicable disease (NCD). These terms are also frequently used mutatis mutandis and in fact within one country, epilepsy may appear within disability laws and policies as a mental condition as well as simultaneously within NCD directives and policies as a stand-alone condition, separate from mental health conditions. The aspect of terminology is important especially in the context of legal protection because the classification of epilepsy has bearing on the legal instrument which should be relied on to support the rights of persons with epilepsy and to hold duty bearers accountable. National strategies may also differ in terms of their implementation frameworks, thus, if epilepsy appears in conflicting instruments with each one assigning a different classification thereto, apart from a duplication of efforts which wastes resources in resource-restricted settings, this could further result in conflicts regarding the management and treatment of epilepsy. Consequently, it is very important for the adoption of cohesive terminology and classification of epilepsy.

In recent times, a number of advocates for the rights of persons with epilepsy have emphasised that although epilepsy may cause disability, it is not intrinsically a disability and that many persons with epilepsy are high functioning, able-bodied individuals. Such observations highlight the importance of treating individual cases on the circumstances presented. However, to further underscore the colossal impact of terminology and classification the ruling made by the Western Cape Division of the High Court of South Africa is notable. The Applicant in the example below was a student at a South African university where he also served a term as a member of the Student Representative Council. The Applicant was diagnosed with epilepsy during the course of his studies. It transpired that the university excluded the Applicant's continuation of studies on the basis that he had exceeded the maximum number of years permissible to complete the relevant qualification. The university makes exceptions or special provisions to this rule for persons with disabilities. While Applicant maintained that epilepsy is a disability and as such, the exceptions against his academic exclusion ought to be applied, his university's Council was adamant that epilepsy is a chronic disease. It is reported by media platforms that the High Court in this application determined that epilepsy is in fact a disability and not a chronic disease as the university had insisted. The decision by the University Council to exclude the Applicant was therefore overturned by the Court.

The Applicant's personal account, as an advocate for students living with epilepsy, appears in the summer 2021 edition of EpiNews published by Epilepsy South Africa. Below is an extract published by Legalbrief Today which also appears on Netwerk24 and Medicalbrief.

"EPILEPSY RULED A DISABILITY BY HIGH COURT

Epilepsy is a disability and not a chronic disease, the Western Cape High Court ruled in ordering Stellenbosch University to reconsider its exclusion of a student who failed to complete his degree in the maximum allowed time. Netwerk24 reports that "W.G" (27), a former student in engineering, launched an application to be reconsidered after his academic exclusion from the programme in mechatronics engineering. He had failed to meet minimum academic standards for six years. "W.G" argued that the university did not treat him as a student with disabilities as it held the view that epilepsy was a chronic disease. The fact that he suffers from epilepsy affects his concentration and memory. The university said it had bent over backwards for "W.G" as a 'special student' and made an exception for him last year to complete his studies, which he was unable to do. Judge Elizabeth Baartman set aside the university council's decision to academically exclude "W.G" and ordered the council to reconsider "W.G" s situation.

Source: Legalbrief Today, 11 September 2020"

7. The role of health laws in supporting the prioritisation of epilepsy

Law plays an important role in terms of supporting the prioritisation of epilepsy on domestic and international levels by setting norms and standards as well as establishing mechanisms through which the goals of the SDGs may materialise. Further, disputes at national and international levels can be resolved through legal remedies. It is also through the law that public and private duty-bearing institutions are governed and held to account.

More relevant to this study is the specific role of health laws which can be used to promote health policy goals such as universal health coverage, the right to the highest attainable standard of health as well as access to quality healthcare and information. Health laws establish the foundation for organising, governing and financing State health systems while also protecting the public and social nature of healthcare. Likewise, it is through the implementation of health laws that the public is protected from the spread of contagious ailments and other public health hazards. Furthermore, NCDs are often addressed through legislation on risk factors for example the imposition of sin-taxes on goods which increase the risk NCDs and regulating their usage in public places.

[6] https://epilepsy.org.za/new/uploads/files/EPINEWSSUMMER202132pp.pdf at page 30-31.

[7] See also: https://www.medicalbrief.co.za/archives/high-court-epilepsy-a-disability-not-a-chronic-disease/ and https://www.netwerk24.com/Nuus/Onderwys/epilepsielyer-mag-ingenieursgraad-aan-us-voltooi-20200925.

Additionally, health laws are imposed to regulate the operation of hospitals, clinics or other health services, control the training and practice standards of health workers such as neurologists or epileptologists as well as to regulate the safety and efficacy of medicines and medical devices such as EEG machines. Lastly, apart from governing the collection and use of health information, health laws form the basis of patient rights like the right to doctor-patient privacy as well as the confidentiality of medical records.

8. Approach to health law

The Constitution of the leading international organisation on health matters, the World Health Organisation (WHO) defines health as follows:

… "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

It is worth noting that various experts opine that the above definition is too rigid and argue that in comparison to the Constitution, the WHO's own Ottawa Charter contains a more encompassing definition which states that health is: "a resource for everyday life. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being".

Nonetheless, the WHO's Constitution further puts forth that it is the fundamental right of all persons to enjoy the most feasible standard of health, irrespective of their race, political ideology, social or economic status. The importance of the health of everyone is linked to peace and security. Thus, disparities between countries in the support for health and the control of [communicable] diseases are regarded as a universal threat. The WHO also calls for the extension of the benefits of medical, psychological and related knowledge which are essential components to the highest attainment of health, to all people. The onus to provide sufficient health and social services is placed on governments.

Health law is considered to be a particular field of law which canvases the health of individuals and populations, the provision of healthcare and the operation of the healthcare system. As such, this study focuses, in chief, on these aspects notwithstanding the numerous ways in which people with epilepsy are affected by other fields of law.

9. What are the domestic legal frameworks that influence a person with epilepsy?

Legal frameworks refer to the outline of existing legal instruments which are not necessarily based on a specific field or subject of the law. Typically, most States bestow a hierarchical order on laws such that it is evident which legal instruments are supreme or hold final authority over disputed matters. For example, a constitution is usually the supreme law of the land which articulates the structure of governance in addition to basic rights and obligations. A constitution may proclaim the right to health and / or access to healthcare for all persons within the territory of the State. Antecedent to the rights to health and access to healthcare is the duty of the State to ensure that these rights are realisable. A constitution may also address the national status of international binding agreements entered into by the State.

[8] WHO Constitution, 1946

[9] WHO Ottawa Charter for Health Promotion (1986), https://www.who.int/healthpromotion/conferences/previous/ottawa/en/.

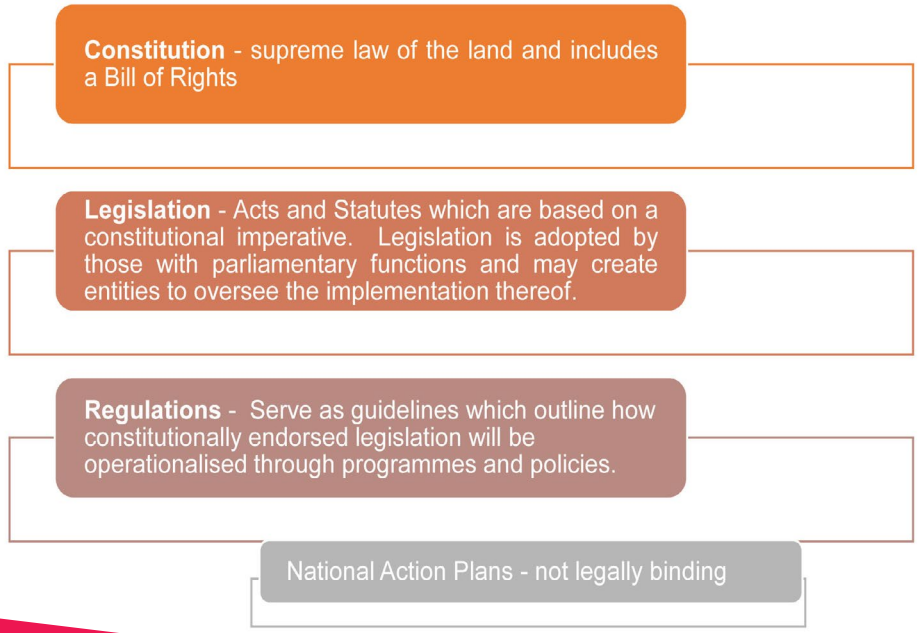
[10] WHO.

Beneath the rank of a country's highest law are other pieces of legislation. Comprehensive legislation may set out the obligations of various actors, procedures to be adhered to in order to achieve particular objectives, as well as prohibited conduct. In relation to the right to health and based on a constitutional imperative, legislation may direct government to establish a focal office to deal with health matters such as a department of health. Legislation may also serve as the basis from which a minister of health draws authority.

To give effect to legislation, it may also be necessary for an empowered entity – for example the department of health, to issue regulations which are thus subsidiary to legislation in the hierarchy of laws. Such regulations provide more information on how constitutionally supported legislative provisions would be operationalised through various activities and policies. National action plans (NAPs) are examples of such policies. Methven et. al describe NAPs as "government-drafted policy documents that articulate State priorities and indicate future actions to support implementation of legal obligations or policy commitments on a given topic". NAPs can thus be considered as mediums through which legal obligations are met.

Concerning whether or not NAPs are legally binding, we must consider that these tools are designed to be complementary to existing legislation and do not usually stand alone. Some have timeframes or validity periods attached to them or are implemented to address temporal situations like pandemics. As such, NAPs are not legally binding but, they certainly ease decision-making processes, facilitate inter-sectoral cooperation, support the monitoring of implementation, encourage the dedication of resources and spur avenues through which governments can be held accountable. Non-legally binding instruments are frequently referred to as "soft law", that is, a quasi-law which relies a great deal on the principle of good faith. Mörth highlights that "soft law" instruments cannot be legally sanctioned for non-compliance.

The frameworks discussed above in hierarchical sequence are the most common domestic legal frameworks that influence the life of a person with epilepsy. The diagram below summarises this.



[11] Methven O'brien, C., Mehra, A., Blackwell, S., & Poulsen-Hansen, C. (2016). National Action Plans: Current Status and Future Prospects for a New Business and Human Rights Governance Tool. Business and Human Rights Journal, 1(1), 117-126. doi:10.1017/bhj.2015.14.

[12] Viljoen (2007) at 28-30.

10. The indivisibility of human rights

Toebes opines that the right to health is accompanied by enforceable rights to a range of health-related services and choices based on the resources available in a State and the health context faced by people in the particular State.

The right to health is mutually dependent on the materialisation of other human rights like equality just as other human rights like the right to life are dependent on the fulfilment of the right to health. To explain briefly and simply: in order to fully enjoy the right to life, fulfilment of the right to health is an essential component and to benefit from the right to health for all, it necessary for the realisation of the right to equality. As a consequence, a violation of the right to equality in relation to the right to health may affect an individual's right to life or at least the quality thereof. This concept is well defined in law as the indivisibility of human rights.

Some schools of thought submit that the indivisibility of human rights – especially rights within the civil and political rights as well as the economic, social and cultural rights categories, means that human rights although distinguishable have greater impact when enforced in tandem. Others interpret indivisibility to mean that all human rights are individually important at the same level such that one right has no hierarchical value over another.

The realisation of the right to health is influenced by other factors such as the rights to food, water, decent living, access to information and the right not to be discriminated against. Likewise, the right to health also contributes to the attainment and enjoyment of these factors.

[13] Mörth (2004) at 2.

[14] Toebes, B. C. (1999). The Right to Health as a Human Right in International Law. Antwerp: Oxford.

[15] WHO, 2008.

1. International and regional treaties

1.1. Committing to International Treaties

A treaty is an agreement between parties subject to international law. More technically, the Vienna Convention on the Law of Treaties terms treaties as a written agreement of an international nature, contained in one or several connected instruments which is regulated by the principles of international law, irrespective of what it is called. The International Law Commission agrees with this definition adding that such an agreement between subjects of international law can be called a *"treaty, convention, protocol, covenant, charter, statute, act, declaration, concordat, exchange of notes, agreed minute, memorandum of agreement, modus vivendi or any other appellation"*

Following negotiated consensus, States become signatories to international treaties through an act of signature. Signing the treaty indicates preliminary endorsement of the instrument and demonstrates a State's goodwill to consider domestication of the instrument. Signing an instrument does not create a binding legal obligation. A State intending to become bound by the provisions of an international instrument may do so by acceding to or ratifying the instrument. Accession and ratification have the same consequence but different steps are followed in both cases. Ratification is preceded by an act of signature followed by the depositing with the United Nations Secretary-General of a formal sealed letter intimating the decision to ratify the international agreement, which has been signed by the State's competent authority – referred to as an instrument of ratification.

However, accession is not preceded by an act of signature and only involves depositing with the United Nations Secretary-General of a formal sealed letter intimating the decision to accede to the international agreement, which has been signed by the State's competent authority – referred to as an instrument of accession. An additional act of commitment to international treaties is domestication. This entails promulgating national laws which support the implementation of the international agreement in accordance with the national laws as they apply to international agreements. This may be done through the creation of new laws or amending existing laws to align with the international agreement.

The international and regional legal instruments regarding the right to health as they relate to the context of this report are now outlined.

a. The UN Declaration of Human Rights (UDHR)

The UN Declaration of Human Rights (UDHR) adopted in 1948 was designed with the intention of clarifying the concepts of fundamental freedoms and human rights as enshrined in the United Nations Charter. While the UN Charter is a binding treaty on all Member States of the UN, there is no consensus on whether the UDHR is

[16] Article 2(1)(a) of the Vienna Convention.
[17] ILC Yearbook 1962 at 161
[18] The Concise Oxford Dictionary Of Current English (8th Edition), Clarendon Press, Oxford, 1990 And United Nations Treaty Collection, Treaty Reference Guide, 1999, Available at Http://Untreaty.Un.Org/English/Guide.Asp.
[19] Ibid.
[20] Ibid.

a binding treaty. Compelling arguments in favour of the UDHR's weight hold that the UDHR has over time become part of international customary law which may be used to persuade violating States on moral grounds.

The full text of Article 25 of the UDHR provides that: *"everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."* Article 25 does not explicitly enunciate health as a human right however it states that everyone is entitled to a standard of living that is sufficient to promote health and well-being. Article 25 further mentions components which would sustain such an adequate standard of living and they include medical care and necessary social services as well as the right to security in the event of sickness and disability.

b. The International Covenant on Civil and Political Rights (ICCPR)

The ICCPR which was adopted by UN member States in 1976 and forms part of the International Bill of Rights extends its protection of civil and political rights to all individuals who find themselves within the territory of a State Party and guarantees the right to non-discrimination. The UN Human Rights Committee which is an arm of the UN Human Rights Council is tasked with overseeing adherence to the principles of the ICCPR.

Article 2 of the ICCPR states as follows:

"1. Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

2. Where not already provided for by existing legislative or other measures, each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such legislative or other measures as may be necessary to give effect to the rights recognized in the present Covenant.

3. Each State Party to the present Covenant undertakes:

(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;

(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal

[21] Ibid.
[22] Ibid.

system of the State, and to develop the possibilities of judicial remedy;

(c) To ensure that the competent authorities shall enforce such remedies when granted."

Through the words *"each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant…"* contained in Article 2, States Parties to the Covenant have the onus of ensuring that domestic laws which support respect for and protection of civil and political rights are implemented. Domestication of the ICCPR is to include the establishment of competent judicial mechanisms with the authority to monitor and enforce civil and political rights.

As has been mentioned, the right to health is interconnected to the rights to life, dignity and equality. The ICCPR states that all human beings have the inherent right to life and shall not be arbitrarily deprived of this right. The Human Rights Committee has ruled that this right should be not be interpreted in a restrictive manner as has often been the case and that States have the duty to favourably act and to "take all positive measures" in order to protect the right to life despite the use of the language "inherent" – interpreted to mean natural or unassisted, right to life".

On the right to dignity, the ICCPR in its Preamble provides that States Parties to the Covenant recognise that the rights contained therein derive from the inherent dignity of people. Furthermore, Article 7 protects all persons from being subjected to cruel or degrading treatment of punishment and specifically from being experimented on for medical or scientific purposes without consent. The right to dignity is afforded to all individuals and this includes persons with neurological conditions and/or mental and physical disabilities. An existence worthy of human dignity is the crux of human rights. It for this reason Dupre asserts that human dignity is the building block and overarching purpose of human rights systems. Dupre further states that the right dignity is the standard to which third generation rights are measured against. Dignity is the thread which binds various rights categories in line with the principle of the indivisibility of human rights.

c. The International Covenant on Economic, Social and Cultural Rights (ICESCR)

According to Article 2 (1) of the ICESCR, States Parties agree to take steps: "… individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

Whereas the previously discussed ICCPR compels States Parties to respect and ensure the realisation of civil and political rights, the

[23] Article 6, ICCPR.

[24] HRC General Comment No. 6: the right to life (Article 6), 1982 Adoption: 30 April 1982, para. 5.

[25] Dupre, 2009.

ICESCR uses more lenient language by only requiring that States do their best within the resources available to progressively attain the economic, social and cultural rights contained in the Covenant. This is known as the principle of progressive realisation and recognises the constraints some resource-restricted countries may encounter in the realisation of rights with economic consequences. Progressive realisation also implies that States are expected to continuously make forward moving actions towards the eventual materialisation of economic, social and cultural rights. To do so, States may enlist the economic support and technical expertise of international entities like UN Agencies and the Bretton Woods institutions.

The nature of the ICESCR fits the method of interpretation described as teleological and this method of interpretation looks at international agreements as "living" instruments rather than being static and "tied to the original intent of States Parties".

Implementation of the ICESCR is monitored by the United Nations' Committee on Economic, Social and Cultural Rights (CESCR) and like the ICCPR, the ICESCR forms part of the International Bill of Rights. The CESCR (the Committee) found that the ICESCR (the Covenant) establishes minimum core obligations on State Parties to facilitate the realisation of economic, social and cultural rights. In the context of limited resources, States are expected to provide the basic aspects of the rights contained in the Covenant. And where there are shortcomings, States should be able to show that all avenues have been exhausted in an attempt to meet their obligations and that the fulfilment of the relevant right(s) has been addressed as a matter of priority for example through the use of programmes that mainstream the vulnerabilities of various population.

Where States Parties endeavour to extinguish their duties in terms of the Covenant, they must do so without discriminating on the ground of race; colour; sex; language; political or other opinion; national or social origin; property; birth or other status.

The rights in the ICESCR may be subjected to limitations by law to the extent that such limitations do not erode the nature of the right concerned and only in the interest of the public in a democratic society. As such, economic, social and cultural rights are not absolute and the non-enforcement of the rights by States may be justified by the lack of adequate resources to do so.

Nonetheless, the ICESCR is taken by many to be the primary international instrument which protects the right to health. Article 12 of the ICESCR states as follows:

"(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

(2) The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

[26] Sheeran, 2013.

[27] CESCR General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant) Adopted at the Fifth Session of the Committee on Economic, Social and Cultural Rights, on 14 December 1990 (Contained in Document E/1991/23).

(a) The provision for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."

From Article 12 we deduce that the duty placed on States is to recognise the right to the highest attainable level of both physical and mental health. The Committee on Economic, Social and Cultural Rights lists non-exhaustive measures States should take in recognising the right of everyone to the enjoyment of the highest attainable standard of health. These steps echo the provisions of Article 12 and include the improvement of infant and maternity health; prevention, treatment and control of epidemic, endemic and other diseases; as well as medical services for the unhealthy.

As mentioned above, when a country embarks on protecting and providing for economic, social and cultural rights, this must be done without discriminating on the ground of race; colour; sex; language; political or other opinion; national or social origin; property; birth or other status. The only limitations which may be placed should be lawful, may not alter the basic purpose of the right and failure to ensure the realisation of the right may only be justified on the basis of limited resources. In the case of the latter, States still have the duty to ensure the progressive realisation of the rights concerned and must show that the State resources available have been maximised as far as possible in an attempt to fulfil obligations. Accordingly, this applies in relation to the right to health. The highest attainable standard of health will therefore be measured in relation to the resources available and where limitations exist in terms of economic resources, States Parties are expected to take all reasonable steps towards the progressive realisation thereof.

On the prohibition against discrimination, the CESCR determined that the ICESCR should be interpreted as widely as possible in order to promote the full protection and realisation of economic, social and cultural rights for all. General Comment 14 of the CESCR also enunciates main factors which affect the progressive realisation of the right to health. These are:

"Availability – *healthcare facilities and programs should be available in sufficient quantity.*

Accessibility – *health facilities should be accessible to all without discrimination, they should be physically accessible, and information concerning health ideas should be accessible. Accessibility should include prisoners and minorities. A health facility must also be accessible in the sense of being affordable.*

[28] Article 4, ICESCR.

[29] CESCR General Comment No. 14 on Article 12.

[30] CESCR General Comment No. 9, para. 15.

Acceptability – *health facilities and services should be respectful of medical ethics and culturally appropriate.*

Quality – *health facility, goods and services should be scientifically and medically appropriate, of good quality, skilled medical personnel, and unexpired drugs and medical equipment.".*

d. The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

Article 10 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) which entered into force in 1971 seeks to eradicate discrimination and disparity against women by encouraging States Parties to implement initiatives targeted at ensuring equality of men and women, including by ensuring "access to specific educational information to help to ensure the health and well-being of families". Further, that States Parties shall adopt suitable efforts to abolish discriminatory healthcare practices against women so that women have equal access to healthcare services as men. Although the CEDAW focuses squarely on women's human rights, it is important to note its provisions in the present context of epilepsy health laws as research has shown how women with epilepsy are frequently subjected to greater social stigma and discrimination which are tied to cultural and social constructs.

e. The Convention on the Rights of the Child (CRC)

The right to health for children as a specific group of persons is enshrined in the Convention on the Rights of the Child (CRC) which entered into force in 1990. Article 24 is clear that all children have the right to "the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health." Moreover, States Parties are expected to work towards making sure that no child is barred from accessing both preventive and curative healthcare services.

The concept of primary healthcare aims to make essential health care for relatively common conditions more accessible and is often linked to reduced costs of State sponsored service provision for healthcare consumers. The CRC encourages attention to the development of primary healthcare in order to fully implement the right of all children to the highest attainable standard of healthcare.

Also of note is the acknowledgement of how some traditional practices may be harmful to the health of children and in this regard, States Parties are implored to adopt "effective and appropriate measures with a view to abolishing" such practices. The special needs of mentally and physically disabled children are also recognised in Article 23. This provision is of particular relevance in the contexts wherein epilepsy is classified as a disability.

[31] CESCR, General Comment 14
[32] Article 10(h) of CEDAW.
[33] Article 24 of the CRC.
[34] Article 24(2)(b) of the CRC.
[35] Article 24(3) of the CRC.

f. Convention on the Rights of Persons with Disabilities (CRPD)

Further on the aspect of disabilities, the Convention on the Rights of Persons with Disabilities (CRPD) which entered into force in 2008 takes on a broad definition towards disabilities. This instrument is often hailed as the first comprehensive human rights treaty of the 21st century in the sense that it addresses a dynamic range of rights for persons with disabilities including protection from discrimination on the basis of disability and has a social development dimension. Article 25 of the CRPD addresses the aspect of health for persons with disability and acknowledges their right to "the enjoyment of the highest attainable standard of health without discrimination on the basis of disability". On this note, States Parties are implored to:

"a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people's own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability".

The diverging views concerning the terminology and classification of epilepsy have been discussed. The above internationally binding provisions are important in the context of epilepsy which is often classified by States or socially assumed by the generally population in several African countries to be a disability. Nonetheless, considering that no international treaty on the explicit rights of persons with neurological conditions or non-communicable diseases exists, the CRPD is presently the most legally binding international agreement that persons with epilepsy may seek guidance from vis-à-vis international norms and standards. Finally, the CRPD also contends with statistics and data collection in Article 31. The collection of information in this context falls into the purview of health laws, as

[36] Article 23(1) – (4) of the CRC: "1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. 2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child. 3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development 4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries."

explained earlier in this report on the role of health laws in supporting the prioritisation of epilepsy.

This discussion now turns to look towards five African regional treaties, namely: the African Charter on Human and Peoples' Rights, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, the African Charter on the Rights and Welfare of the Child as well as the African Youth Charter.

g. African Charter on Human and Peoples' Rights (African Charter/ACHPR)

The African Charter on Human and Peoples' Rights, commonly referred to as the African Charter or ACHPR, places the onus on States Parties to "take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick". Article 16 guarantees that every individual in a States Party to the ACHPR has the right to enjoy "the best attainable state of physical and mental health". Persons with disabilities receive mention in Article 18 which stipulates that they have the right to "special measures of protection in keeping with their physical and moral needs". It took over 30 years since the adoption of the ACHPR for the OAU/AU to approve a more comprehensive binding instrument that is specific to the rights of persons with disabilities and this is briefly summarised now.

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

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa which was adopted by the AU in 2018 protects the human rights of persons with disabilities and further recognises the "diversity of persons with disabilities". The AU Disability Protocol defines persons with disabilities as inclusive of "those who have physical, mental, psycho-social, intellectual, neurological, developmental or other sensory impairments which in interaction with environmental, attitudinal or other barriers hinder their full and effective participation in society on an equal basis with others". It is notable that such a description is wide as it is not limited to physical and mental health but also recognises neurological, developmental and sensory health. Furthermore, the AU Disability Protocol acknowledges the impact of external factors such as social barriers which have an effect on the enjoyment on the rights of persons with disabilities.

States Parties to the AU Disability Protocol are urged to implement apt and valuable measures which include policy, administrative, financial, institutional and legislative efforts aimed at ensuring, promoting, respecting, protecting and fulfilling the rights and inherent dignity of persons with disabilities. This incorporates mainstreaming considerations of disability matters into domestic legislation, policies and strategic development plans.

[37] A Article 1 of the CRPD: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

[38] Article 2 of the CRPD: "Discrimination on the basis of disability" means any distinction, exclusion or restriction 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, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation"

[39] Article 3 of the CRPD: "The principles of the present Convention shall be: (1) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (2) Non-discrimination; (3) Full and effective participation and inclusion in society; (4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (5) Equality of opportunity; (6) Accessibility; (7) Equality between men and women; (8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

Further, the constitutions and other legislative instruments of States Parties must repeal or abolish discriminatory policies, regulations and laws which infringe on the rights of persons with disabilities.

Specifically on the right to health, the AU Disability Protocol details, as examples, a host of measures which are deemed appropriate and effective towards realising the right of every person with a disability to the highest attainable standard of health. These include:

1. Equal range, quality and standard of free or affordable health care as other persons;
2. Tailored health services or services designed to minimise or prevent further disability;
3. Prohibitions against discrimination by health service or insurance providers;
4. The provision of health services in the community;
5. Targeted but non-stigmatising health campaigns; and
6. Training healthcare providers to be sensitive to the specific needs of persons with disabilities.

As at the time of the compilation of this report, the AU Disability Protocol is yet to come into force primarily because it has not met its own requirement of fifteen ratifications. Although nine States have signed the Protocol, none have ratified the instrument. Therefore, despite its pioneering status, it is not yet in force. To recap, signing an instrument indicates preliminary endorsement of the instrument and demonstrates a State's goodwill to consider domestication of the instrument. Signing an instrument does not create a binding legal obligation.

In October 2019, the Pan African Parliament adopted its Model Disability Law which aims to facilitate the domestication of the African Disability Protocol in States Parties.

i. The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol / Maputo Protocol)

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol) places the duty on States Parties to guarantee that the health and reproductive rights of women are respected and promoted. Encompassed in these rights which are articulated in Article 14 of the African Women's Protocol, are the freedoms to control fertility as well as the choice to have children. As such, all women under the protection of States Parties to the African Women's Protocol, irrespective of their health conditions such as epilepsy, have the right to determine their reproductive choices. States Parties are obliged to provide adequate, affordable and accessible health services, particularly for women in rural areas.

[40] Article 25 of the CRPD.

[41] Article 31 of the CRPD: "1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall: a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities; b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics. 2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. 3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others."

j. The African Charter on the Rights and Welfare of the Child (African Children's Charter)

The African Charter on the Rights and Welfare of the Child (African Children's Charter) aims to protect the rights of all children in States Parties including those with physical and mental disabilities. These children have the right to "special measures of protection in keeping with their physical and moral needs and under conditions which ensure dignity, promote self-reliance and active participation in the community". All children are guaranteed the right to enjoy the best attainable state of physical, mental and spiritual health. The range of measures States Parties must implement to fulfil this obligation include:

1. Reducing infant and child mortality rates;
2. Ensuring the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
3. Combating disease within the framework of primary healthcare through the use of appropriate technology. This presumptively would include epilepsy diagnosis and treatment technology;
4. Integrating basic health service programmes into national development plans; and
5. Ensuring meaningful participation of non-governmental organizations, local communities and the beneficiary population in the planning and management of basic service programmes for children.

k. The African Youth Charter

Finally, the African Youth Charter protects the right of African Youth in States Parties to enjoy the best attainable state of physical, mental and spiritual health. While the African Youth Charter focuses on the aspect of health in relation to HIV/AIDS and substance abuse control, States Parties are enjoined to provide fair and easily accessible medical support and healthcare as well as to develop primary healthcare, including in rural and impoverished urban regions. Additionally, States Parties should grant technical and financial assistance to boost the capacity of youth organisations to tackle public health matters such as youth with disabilities.

Many of the international and regional treaties that have been analysed in this report in the context of health laws recognise health concerns for various groups such as women, children, youth and persons with disabilities; however, it is only the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa which specifically mentions health aspects in

[42] Article 16(2) of the ACHPR.
[43] Article 16(1) of the ACHPR.
[44] Article 18(4) of the ACHPR.
[45] Article 4 of the African Disability Protocol.

the milieu of neurological conditions. It has been highlighted that this instrument is yet to take effect since no African State has ratified it.

I. Monitoring the implementation of treaties

In terms of monitoring the implementation of treaties, most human rights treaties have accompanying treaty bodies comprised of independent experts whose task it is to oversee implementation and reporting mechanisms. Comprehensive treaties establish their own reporting mechanisms and thus oblige States Parties to submit periodic reports to the competent treaty body. A summary of the treaty bodies linked to the international and regional treaty bodies discussed in this report is now provided.

Treaty	Treaty body	Comments
ICCPR	Human Rights Committee on Civil and Political Rights	
ICESCR	Committee on Economic Social and Cultural Rights	
CEDAW	Committee on the Elimination of Discrimination Against Women	
CRC	Committee on the Rights of the Child	
CRPD	Committee on the Rights of Persons with Disabilities	All States parties must submit reports to the Committee. States Parties must report initially within two years of accepting the Convention and thereafter every four years.
ACHPR	African Commission on Human and People's Rights	State Parties are required to submit reports every two years.
African Disability Protocol		Treaty not yet in force
African Women's Protocol	-African Commission on Human and People's Rights -Special Rapporteur on the Rights of Women in Africa	Article 62 of the African Charter and Article 26 (1) of the African Women's Protocol obligates States Parties to submit State reports every two years indicating legislative and other measures undertaken towards the full realisation of the Protocol.
African Children's Protocol	-African Committee of Experts on the Rights and Welfare of the Child (ACERWC) - Working Group on the Rights of Children with Disabilities established in 2020	Ordinary Session held twice a year: March or April and November. During Ordinary Sessions, States Parties reports, complementary reports by CSOs, communications, requests for investigation and other requests submitted before the Committee are examined.
African Youth Charter		No monitoring body

[46] See https://au.int/sites/default/files/treaties/36440-sl-PROTOCOL%20TO%20THE%20AFRICAN%20CHARTER%20ON%20HUMAN%20AND%20PEOPLES%E2%80%99%20RIGHTS%20ON%20THE%20RIGHTS%20OF%20PERSONS%20WITH%20DISABILITIES%20IN%20AFRICA.pdf.

[47] The Concise Oxford Dictionary Of Current English (8th Edition), Clarendon Press, Oxford, 1990 And United Nations Treaty Collection, Treaty Reference Guide, 1999, Available at Http://Untreaty.Un.Org/English/Guide.Asp.

Paul Hunt argues that if the right to health is to be enforced, it must explicitly be interpreted in line with international human rights law and through a strategy built on a rights-based approach. He acknowledges that this could compound further discourse such as:

i. The importance of distinguishing between the human rights which may be progressively realised and those which may not;

ii. A clear articulation of the fact that while there are some "core obligations" on all States Parties such as the duty to ensure equitable access for all and the duty to target the marginalised in health strategies, the right to health places increased burden on so called high-income countries in comparison to low-income countries – because high-income countries with more resources are held to a higher standard in measuring their extinguishing of this duty; and

iii. The responsibility of those capable of doing so to render international support and cooperation in the health sector, particularly to lower-income countries – or "developing countries" as is the term used in the ICESCR.

The right to health is on occasion misinterpreted as the right to healthcare. Das opines that the right to healthcare is a limited concept which is confined to services associated to health such as preventative, curative and palliative health services. To recount prior discussions in this report, health is defined in the World Health Organisation's Constitution as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The right to health therefore is the entitlement to enjoy the highest attainable standard of holistic physical, mental and social well-being. On the other hand, healthcare as a right refers to the accessibility, availability, acceptability and quality for all of hospitals, clinics, medicines and doctors. Baharul Islam provides that the establishment of a good healthcare system should comprise of the following critical standards:

*"**Universal Access:** Access to health care must be universal, guaranteed for all on an equitable basis.*

***Availability:** Adequate health care infrastructure (e.g. hospitals, community health facilities, trained health care professionals), goods (e.g. drugs, equipment), and services (e.g. primary care, mental health) must be available in all geographical areas and to all communities.*

***Acceptability and Dignity:** Health care institutions and providers must respect dignity, provide culturally appropriate care, be responsive to needs based on gender, age, culture, language, and different ways of life and abilities.*

***Quality:** All health care must be medically appropriate and of good quality, guided by quality standards and control mechanisms, and provided in a timely, safe, and patient-centered manner.*

***Non-Discrimination:** Health care must be accessible and provided without discrimination.*

***Transparency:** Health information must be easily accessible for everyone.*

***Participation:** Individuals and communities must be able to take an active role in decisions that affect their health.*

***Accountability:** Private companies and public agencies must be held accountable for protecting the right to health care."*

Earlier discussions on the indivisibility of human rights established that there is a nexus between health and the quality of life. This review of international instruments and their interpretations by various committees finds

[48] Ibid.

[49] Article 14(2)(a) of the African Women's Protocol".

[50] Article 13(1) of the African Children's Charter.

[51] Article 14(2) of the African Children's Charter.

[52] Article 16 of the African Youth Charter.

that the right to health extends well beyond healthcare to include basic preconditions for health, such as potable water and adequate sanitation and nutrition. Just as the WHO Constitution asserts, health is also presented by Eade as an essential factor in development. However, in recognising that the realisation of certain rights may be a challenge for less developed and developing States, States Parties to the ICESCR agreed on the principle of "progressive realisation".

Thus, governments are tasked with the responsibility to make strides towards progressively realising economic, social and cultural rights. The duty on States as far as the right to health is concerned therefore is one of progressive realisation. However, despite the precise language used in international instruments which extend the right to health to all persons, there are often disparities between the rights in the international agreements States ratify and the experiences of marginalised groups. The summary table which follows analyses the state of ratifications of the instruments discussed above by the 21 countries studied in this report.

m. Summary table of ratifications (international and regional instruments)

	ICCPR	ICESCR	CEDAW	CRC	CRPD	ACHPR	AU Disability Protocol	Maputo Protocol	African Children's Charter	African Youth Charter
Angola	X	X	X	X	X	X	S	X	X	X
Botswana	X	-	X	X	-	X	-	-	X	-
Cameroon	X	X	X	X	S	X	S	X	X	X
Comoros	S	S	X	X	X	X	-	X	X	S
DRC	X	X	X	X	X	X	-	X	S	S
Eswatini	X	X	X	X	X	X	-	X	X	X
Kenya	X	X	X	X	X	X	-	X	X	X
Lesotho	X	X	X	X	X	X	-	X	X	X
Madagascar	X	X	X	X	X	X	-	S	X	S
Malawi	X	X	X	X	X	X	-	X	X	X
Mauritius	X	X	X	X	X	X	-	X	X	X
Mozambique	X	-	X	X	X	X	-	X	X	X
Namibia	X	X	X	X	X	X	-	X	X	X
Nigeria	X	X	X	X	X	X	-	X	X	X
Rwanda	X	X	X	X	X	X	S	X*	X	X
Seychelles	X	X	X	X	X	X	-	X	X	X
Sierra Leone	X	X	X	X	X	X	-	X	X	S
South Africa	X	X	X	X	X	X	S	X	X	X
Tanzania	X	X	X	X	X	X	-	X	X	X
Zambia	X	X	X	X	X	X	-	X	X	X
Zimbabwe	X	X	X	X	X	X	-	X	X	X

Key- S: Signed **X**: Ratified **X***: Ratified with reservations on the right to health

[53] Hunt, P., Interpreting the International Right to Health in a Human Rights-Based Approach to Health in Health Human Rights (Dec 2016); 18(2): 109–130.

[54] Das, 2013.

[55] Eade, 1997.

Section D

1. Country analysis

The analysis which follows is primarily based on a desk review of the hierarchical domestic laws and policies in the countries under study. The instruments analysed are those which relate to the health laws of the country and more specifically to the context of epilepsy through its varying classifications as a disability, a mental health condition/illness, a neurological condition and/or an NCD. The information presented seeks to enable comparative analysis between States as well as to support monitoring of the state of advancement and implementation of international resolutions on epilepsy.

Country: Angola						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	-Article 77: The State shall promote and guarantee the measures needed to ensure the universal right to medical and health care, as well as…care in illness, disability… and in situations in which they are unable to work, in accordance with the law. -Article 80(3): the State shall ensure special protection to children who are orphaned, disabled, abandoned or in any way deprived from a family environment. -Article 83(1): disabled citizens shall fully enjoy the rights and be subject to the duties enshrined in the Constitution, without prejudice to any restrictions on the exercise or fulfilment of rights and duties they are unable, or not fully able, to enjoy or carry out. -Article 83(2): The State shall adopt a national policy for the prevention of disability, the treatment, rehabilitation and integration of disabled citizens, the provision of support for their families and the removal of obstacles to mobility. Article 84(1): …those disabled during the course of military or paramilitary service…shall enjoy … the protection of the State and society, under the terms of the Constitution and the law. -No explicit recognition of the right to "the highest attainable standard of physical and mental health" in line with international and regional instruments.	Basic Law of the National Health System, 1992 (*Lei de bases do systema nacional de saúde*)	National Health Development Plan (*Plano Nacional de Desenvolvimento de Saúde*)	Section on chronic non-communicable diseases (*doenças crónicas não transmissíveis*) acknowledges a lack of epidemiological data on chronic non-communicable diseases which are said to constitute a double burden together with the prevalence of communicable diseases. A list of chronic NCDs is provided with no mention of epilepsy. Calls for more research on chronic NCDs.	2012-2025	
		Basic Law of Social Protection (*Lei de bases da protecção social*)				
			National Development Plan (*Plano De Desenvolvimento Nacional, Decreto Presidencial n.º 158/18 de 29 de Junho)*	Significant reference to NCDs, epilepsy not mentioned amongst those highlighted. Priority actions include health prevention and promotion campaigns and screenings for NCDs; reducing morbidity and mortality rates for NCDs The National Development Plan directs for the creation and operation of the National Committee for the Coordination of Chronic Non-Communicable Diseases as well as the creation of a network of services for attending to carriers of Chronic NCDs and factors related risks. Highlights that diseases and technology related to NCDs should be considered a priority with related assistance	2018-2022	

Country: Angola						
			Strategy to protect persons with disabilities (*Estratégia de protecção à pessoa com deficiência*), 2011	Strategy to materialise what is established in the Basic Law of Social Protection specifically as it relates to persons with disabilities. Includes interventions in the field of health. Monitoring and evaluation processes are to be supported through the use of a database as an instrument that will make monitoring indicators measurable.		
			National Strategy on Human Rights (*Estratégia* Nacional *dos Direitos Humanos)*, 2020	Specific objectives concerning the realisation of economic, social and cultural rights include: to guarantee the progressive, sustainable and effective enjoyment of economic, social and cultural rights for all citizens under conditions of equality; to apply targeted measures to vulnerable people and groups; as well as to ensure adequate response in relation to primary obligations regarding economic, social and cultural rights, for example: the right to health,		
Implementation	Implementation Plan of the Convention on the Rights of Persons with Disabilities	**Summary of survey feedback** *No Data*				
Monitoring	**Actors**	**Comments**				
	National Council of the Person with Disabilities	Monitors implementation of the CRPD and evaluates policy performance created through the Decree Presidential No. 105/12				
	Ministry of Assistance and Social Reintegration	In charge of directing and coordinating the execution of social policy				
	Ministry of Justice and Human Rights	Proposes the formulation of human right s law and policies, as well as conducts, executes and evaluates policies of justice and of promotion, protection and observance of human rights				
	Ministry of Health					

Country: Botswana						
Domestic legal and policy framework	**Constitution**	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
	The right to health is not explicitly contained in the Constitution. However, the rights to non-discrimination and equality are enshrined in Section 15.	Public Health Act: Sections on NCDs (135-148). Considers programmes to prevent, detect, investigate, treat or control NCDs as public health services. Supports the right to basic health services for NCDs. Protects privacy of health records of persons with NCDs.	Multi – sectoral strategy for the prevention and control of non-communicable diseases	While recognising a broader definition of NCDs, the strategy document is clear that the focus is on 4 NCDs namely: cancers, cardiovascular diseases, diabetes, chronic respiratory diseases. No mention of epilepsy or neurological disorders in general either.	2018-2023	
		Mental Disorders Act of 1969: details procedures to be followed in reception and detention cases for mental disorders but does not cover rights protections for persons with mental disorders. The Act has 3 categories of patients including: 1. those who pose a risk to themselves (e.g. suicidal) or others (e.g. homicidal). 2. those who are vulnerable to abuse, cannot look after themselves, and require skilled medical attention; and 3. Those who are vulnerable to abuse but do not require skilled medical attention. In the absence of definitive classification of	Infant and Child Policy, 2015	Supports focused attention on the first 1000 days of life (conception to 24 months of age), so that the essential building blocks for brain development, healthy growth, a strong immune system and protection against non-communicable disease later in life are assured.		
			National Policy on Care for People with Disabilities, 1996	Another draft policy under consideration which seeks to align with the CRPD – which Botswana is not a State Party to.		
			National Policy on Mental Health, 2003	Provides a framework for the incorporation of the objectives of the mental health care services		

Country: Botswana						
		epilepsy, this Act may be applicable to persons with epilepsy in Botswana depending on their individual health circumstances.	National Development Plan	Reflects on challenges identified such as inadequate health services for persons with disabilities and also makes reference to NCDs of which examples provided do not include neurological disorders. Provides that national primary health care guidelines will be implemented as a vehicle for integration of NCD services at primary level.	2017 – 2023	
Implementation		**Summary of survey feedback** - Survey feedback highlighted the perceived lack of prioritisation of epilepsy at national level. - Participants submitted that various terms are used interchangeably to classify epilepsy. As such, people with epilepsy are at risk of arbitrary applications of laws and policies depending on the circumstances they find themselves in. - Limited engagement between the State and epilepsy NGOs, thus, there is also little knowledge amongst non-State actors on the level of plans to prioritise epilepsy				
Monitoring	**Actors**	**Comments**				
	Public Health Director	The Director shall ensure that the provision of services for the management, prevention and control of non-communicable diseases is efficient (Section 138 of the Public Health Act)				
	Minister of Health and Wellness	Tasked with prescribing the procedures to be followed by users of health services for laying complaints regarding the provision of health services; and establishing mechanisms to inform the users of health services of the complaints procedures (Section 146 of the Public Health Act)				
	Coordinating Office for People with Disabilities in the Office of the President	Onus to develop and coordinate the implementation of policies, strategies and programs through mainstreaming them into development agenda to empower people with disabilities. Also manages the Sir Seretse Khama Memorial Fund (SSKMF) which was established by statutory instrument to support persons with disabilities with “assistive devices”.				

Country: Cameroon						
	Constitution	**Legislation**	**Regulations & Policies**			**Epilepsy NAP**
					Validity	
Domestic legal and policy framework	No explicit right to health. However, the Constitution contains provisions on State support for the disabled.	Law N° 2010 / 002 of 13 April 2010 on the protection and promotion of persons with disabilities: disability defined as: a limitation of the opportunities of a person with impairment to full take part in an activity in a given environment	Decree N° 2018/6233 fixing the procedures of Law N° 2010 / 002 of 13 April 2010 on the protection and promotion of persons with disabilities	Provisions apply to persons with disabilities holding a National Disability Card and justifying a Permanent Potential Incapacity Rate (IPP) of at least fifty percent (50%)		
		Law No. 96/03 of 4 January 1996 Covering the Framework in the Field of Health	Decree No. 2013/093 of 3 April 2013 on the organisation of the Ministry of Public Health.			
			National Health Development Plan (NHDP)	Outdated cycle. No accessible information on state of current NHDP. Discusses NCDs and mentions epilepsy and other neurological diseases as a priority area (Group 4 diseases)	2016-2020	
			Health Sector Strategy (Strategié Sectorielle de Santé)	Amongst other diseases, the document addresses NCDs and has explicit references to epilepsy and other neurological diseases as one of the 5 groups of diseases focused on (Group 4 diseases). According to the Health Sector Strategy (HSS) “implementation of a strategic plan to control epilepsy is not optimal; however, there is a national management guide for medical personnel, and a community management guide”. The HSS further considers epilepsy in its implementation strategies which include: increasing human and financial resources, strengthening initial and continuous training in mental health fields, the prevention of epilepsy and other neurological diseases; and strengthening education and	2016-2027	

Country: Cameroon						
				raising awareness of the population to enable them avoid risk factors. Epilepsy is also identified in the HSS' specific objectives for prioritisation during the 2021 – 2027 cycle.		
Implementation		**Summary of survey feedback** - Feedback highlighted the lack of prioritisation of epilepsy in national health agendas. - By way of assumption, epilepsy health rights are protected through disability laws which have further pre-requisites. For example, the provisions of the Decree N° 2018/6233 fixing the procedures of Law N° 2010 / 002 of 13 April 2010 on the protection and promotion of persons with disabilities only apply to persons with disabilities holding a National Disability Card and justifying a Permanent Potential Incapacity Rate (IPP) of at least fifty percent (50%). - Limited engagement between the State and non-State epilepsy associations. - Evidently very little public knowledge that epilepsy is a priority in the Health Sector Strategy (HSS) 2016-2017				
Monitoring	**Actors**	**Comments**				
	Ministry of Public Health					
	Integrated Monitoring and Evaluation Plan (2016 -2020) -IMEP	- IMEP monitors the planned interventions of the NHDP (2016-2020) at the central, regional and operational level - Specific objectives are: o specifying the institutional and organizational framework for monitoring and evaluation of the 2016- 2020 NHDP; o providing follow–up's simplified tools at all levels of the health pyramid ; o enabling the assessment of the progress made at all levels; o developing the indicator matrix, the performance framework, the dash board for the monitoring of the implementation of the NHDP at all levels of the health pyramid; o defining monitoring and evaluation indicators and mechanisms of the NHDP; and o making a summary description of mid-term and final monitoring and evaluation modalities of the NHDP.				

Country: Comoros						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	Recognises that all citizens have the right to health. The State has a responsibility to provide health service that is general and hierarchical (Section 42)	Law no.95 Relative to the Code of Public Health and Social Welfare for the well being of the population (*Loi no.95 Portant Code de la santé publique et de l'action sociale pour le bien être de la population*): includes protections for persons with disabilities	Accelerated Growth and Sustainable Development Strategy (SCA2D)		2018-2021	
			National Policy to Prevent and Fight Non-communicable Diseases (stratégie nationale de prévention et de lutte contre les maladies non transmissibles)	Tackles NCDs and pays specific focus to particular NCDs including disabilities (handicaps) and mental health. No mention of epilepsy.		
			National Health Policy (Politique Nationale de Santé)	Highlights the challenges posed by the increase in prevalence of NCDs and also discusses mental health issues. Early detection and management of NCDs are priority areas.	2015-2024	
			National Health Development Plan (Plan National de Développement Sanitaire)			

Country: Comoros		
Implementation	Reports submitted to the CCPR in previous years have made comments on the protection of persons with disabilities	**Summary of survey feedback** *No Data*
Monitoring	**Actors**	**Comments**
	Ministry of Public Health	
	The National Commission for Human Rights and Freedoms (CNDHL)	Established by Law No. 11-028 / AU of 23 December 2011 to protect and promote human rights. Further monitors the implementation of international human rights treaties
	FCDH (Comorian Federation of Human Rights)	National NGO which promotes and protects human rights of vulnerable groups including people living with disabilities.

Country: Democratic Republic of Congo						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	Guarantees the right to health (Section 47) and delegates the following to the exclusive competence of Provincial authorities: the assignment of the medical personnel, in accordance with the status of the career officers of the public services of the State, the drafting of programs of sanitation and of the struggle against endemic/epidemic diseases in accordance with the national plan: the organization of the services for provincial hygiene and prophylaxis, the application and control of the national medical and pharmaceutical legislation as well as the organization of the services of curative medicine, of philanthropic and missionary services, of medical laboratories and of pharmaceutical services, of the organization and promotion of primary health care (Section 204(18)).	Law no. 18/035 of December 13, 2018 establishing the fundamental principles relating to the organization of public health (Loi n° 18/035 du 13 décembre 2018 fixant les principes fondamentaux relatifs à l'organisation de la Santé publique): defines health as a state of complete physical, mental and social well-being not consisting only of the absence of disease or infirmity. Counts the protection of people living with disabilities, the mentally ill and other vulnerable groups as part of the scope of public health (Section12). Addresses NCDs (Section 107) in no detail but implies that NCDs are under the purview of the National Council for the Management of Epidemics, Emergencies and Disasters established by Section 106.	National Health Development Plan (PNDS 2016 – 2020 du MSP)	No explicit reference to epilepsy. Addresses NCDs and mentions a few such as diabetes and cardiovascular disease	2016-2020	
		Law on the Protection of the Rights of Persons with Disabilities approved by the National Assembly is pending further approval by the Senate (December 2020)				

Country: Democratic Republic of Congo		
Implementation		**Summary of survey feedback** -Survey feedback highlights the absence of legal protection against those with epilepsy who are subjected to stigma and discrimination. -Draft legislation concerning the protection of the rights of persons with disabilities has been pending for several years and only reached advanced stages of progress in 2020. -Discrimination in the community and health sector mentioned as a concern. -There are no laws which sufficiently address epilepsy, other neurological disorders, mental health or disabilities. Therefore, persons with epilepsy rely on general health laws which do not address the unique challenges related to abhorrent social stigma. -Notably, the DRC has a Minister "Delegate" to the Minister of Social Affairs for People with Disabilities and Vulnerable Persons.
Monitoring	**Actors**	**Comments**
	National Council for the Management of Epidemics, Emergencies and Disasters	Deals with: 1. the development of specific measures to reduce risks and deal with the occurrence of epidemics, disasters and public health emergencies of national or international concern; 2. mobilising national and international skills as well as the necessary resources to support the fight against the harmful effects of epidemics, disasters and public health emergencies.
	Minister of Social Affairs, Humanitarian Action and National Solidarity	Overall responsibility for care of persons with disabilities with delegated authority and functions to the Minister Delegate for People with Disabilities and Vulnerable Persons
	Minister Delegate for People with Disabilities and Vulnerable Persons	Established in 2019 and draws delegated authority from the Minister of Social Affairs, Humanitarian Action and National Solidarity.
	Inter-ministerial Monitoring Committee of the International Convention on the Rights of Persons with Disabilities and its Optional Protocol	Established by Ministerial Order No. 350, November 2016 on the creation, organising and functioning of the Inter-ministerial Monitoring Committee of the International Convention on the Rights of Persons with Disabilities and its Optional Protocol.

Country: Kingdom of Eswatini						
Domestic legal and policy framework	**Constitution**	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
	No specific provision on the right to health. But, one of the identified social objectives states: "without compromising quality, the State…shall take all practical measures to ensure the provision of basic health care services to the population" Section 60(8).	Public Health Act, 2012 Child Protection and Welfare Act, 2012: asserts the rights of children with disabilities, protection from harmful and degrading treatment, against ill-treatment and neglect	National Health Policy	Objectives include reducing morbidity, disability and mortality that is due to diseases and social conditions. The National Health Policy states that health services shall be provided free of charge to eligible children, elderly persons, orphans and persons with disability. A priority area of the policy is the prevention and control of non-communicable diseases.		
		Persons with Disability Act, 2018: seeks to promote and develop the quality of life and wellbeing of persons with disabilities, including through access to health (Section 33)	National NCD Prevention and Control Policy, 2016	Acknowledges the prevalence of epilepsy as an NCD. Lists epilepsy as a priority area of the National NCD Programme established by the Ministry of Health.		
		Mental Health Order, 1978	Mental Health Policy, 2013	(draft)		
Implementation		**Summary of survey feedback** -Lack of implementation frameworks, plans and appropriate budgets to support well conceived policies -Perception that relevant policies are frequently drafted, or at least processes are initiated in that regard, however, there is no feedback on the outcomes. -The intended beneficiaries and affected stakeholders have limited opportunities for engagement on policy recommendations or are unaware of the policy making processes -Concerning the enjoyment of health rights for persons with epilepsy, the following were identified as the main challenges: consultation fees, poor service provision including attitudes and perspectives of service providers, personal sentiments i.e. people feel shy, embarrassed to claim their health rights and in so doing reveal their condition, attitudes and perspectives of home care givers i.e. family is not concerned as well as cultural and/or religious reasons. -Conflicting views concerning the classification of epilepsy in Eswatini as a mental health condition/illness, an NCD or a disability. -Non-State entities providing support to persons with epilepsy have limited authority and resources however, in terms of visibility these entities are seen to have more direct engagement with persons with epilepsy and those affected.				

Country: Kingdom of Eswatini		
	Actors	**Comments**
Monitoring	National Advisory Council for Persons with Disabilities	Established by Section 3 of the Persons with Disability Act, 2018 to promote inclusivity, improve the socio-economic status of persons with disabilities, ensure equal access to health services and ensure that policies do not have negative impact on the status of persons with disabilities and particular vulnerable groups. Further, the Council is tasked with overseeing and monitoring the status of the National Policy and National Plan of Action relating to persons with disabilities as well as to ensure the adoption of and compliance with international declarations and conventions relating to the rights of persons with disabilities (Section 9).
	Ministry of Health	
	Department of Social Welfare	

Country: Kenya						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	In line with international instruments such as the ICESCR, the Constitution stipulates that every person has the right to the highest attainable standard of health, which includes the right to health care services. Section 53 also emphasises the right of children to healthcare. Section 56 on minorities and marginalised groups obligates the State to provide affirmative action programmes to ensure that, amongst other provisions, minorities and marginalised groups have access to health services.	Health Act, 2017: provides that it is a fundamental duty of the State to observe, respect, protect, promote and fulfil the right to the highest attainable standard of health including reproductive health care and emergency medical treatment by inter alia … ensuring the realization of the health related rights and interests of vulnerable groups within society, including…persons with disabilities. It is also in terms of this instrument the duty of the national government to put in place policy intervention measures to reduce the burden of NCDs and neglected diseases, especially among marginalized and indigent populations.	National Strategy for the Prevention and Control of NCDs	Aims to reduce the preventable burden, avoidable morbidity, mortality, risk factors and costs due to Non-communicable diseases and promote the well-being of the Kenyan population by providing evidence based NCD prevention and control interventions in order to ensure optimal health throughout the life course for sustainable socioeconomic development. Specifically mentions epilepsy as an NCD and more specifically, as an example of a neurological condition (Sections on: the linkages between major non communicable diseases and communicable diseases and the synergies between major non NCDs and other chronic conditions)	2015-2020	
		Persons with Disabilities Act, 2003: establishes the National Council for Persons with Disabilities. The Council is to be represented in the implementation of the national health programme in order to, amongst other purposes, ensure the availability of essential health services to persons with disabilities at an affordable cost as well as availing field medical personnel to local health institutions for the benefit of persons with disabilities (Section 20).	Health Policy	The main goal of this policy is to "attain the highest possible standard of health in a responsive manner". The stated objectives include halting and reversing the rising burden of NCDs as well as providing essential healthcare that is efficient, multi-sectoral, equitable and people-centred. While disability and other NCDs are mentioned, epilepsy is not mentioned in the National Health Policy.	2014-2030	

Country: Kenya		
Implementation		**Summary of survey feedback** *No Data.*
Monitoring	**Actors**	**Comments**
	The Kenya Non-Communicable Diseases & Injuries Poverty Commission	"Established to estimate the burden of NCDIs, determine the availability and coverage of health services, prioritize an expanded set of NCDI conditions, and propose cost-effective and equity-promoting interventions to avert the health and economic consequences of NCDIs in Kenya" Its July 2018 report recognises epilepsy as a priority and as an area in which it is recommended that interventions are introduced or scaled-up at the primary healthcare level. The recommended intervention specifically for epilepsy is: "management of epilepsy, including acute stabilization and long-term management with generic anti-epileptics". Epilepsy, is categorised in the Commission's 2018 report as a neurological disease (pg. 43)
	National Council for Persons with Disabilities	Tasked with formulating and developing measures and policies designed to achieve equal opportunities for persons with disabilities by ensuring to the maximum extent possible and recommending measures to prevent discrimination against persons with disabilities;
	Ministry of Health	Overall responsibility to monitor health matters

Country: Lesotho						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	The right to the highest attainable standard of physical and mental health is protected for all citizens (Section 27). This includes polices to improve public health.	Human Rights Act, 1983: provides that every person has the right to enjoy the best attainable state of physical and mental health (Section 14). Further, it is the obligation of the State to implement the necessary measure to protect the health of the people and to ensure that they receive medical attention when they are sick.	National Health Strategic Plan	Identifies epilepsy as one of the most common mental health illnesses in the country and in the same analysis lists epilepsy as one of the main causes of mental health illness (pg. 26). From this, it is discerned that epilepsy is categorised as a mental health illness in Lesotho.	2017 -2022	
		Public Health Bill	National Disability and Rehabilitation Policy (NDRP)	Seeks to identify and remove obstacles to full participation and full equality in society as well as prevent and fight discrimination. Mentions mental illness as an example of disability. Read together with the above National Health Strategic Plan which categorises epilepsy as a mental illness, the NDRP is by extension applicable to persons with epilepsy in Lesotho.		
		Mental Health Law, 1964: Primarily procedural as it relates to the processes of reception and admission of mental health patients as well as the functions of mental health institutions.	National Multi-Sectoral Integrated Strategic Plan For The Prevention And Control Of NCDs	Recognises epilepsy as a predominant NCD as well as a highly common mental health problem. The term “neuropsychiatric mental disorders” is also used with epilepsy as an example.	2014-2020	
		Children’s Protection and Welfare Act: a child shall not be discriminated against on the grounds of … disability, health status …or other status (Section 6). Section 11 protects the right of the child to				

Country: Lesotho						
		health, in particular medical treatment prevented by reason of religious or other beliefs.				
Implementation		**Summary of survey feedback** - Despite the recurring references to epilepsy in national health policies, feedback from the survey highlighted that epilepsy healthcare in the country is neglected - There is also a reported shortage of trained professionals to deal with epilepsy cases. This contributes significantly to the lack of awareness on epilepsy issues in the country. - Discrimination and cultural/religious reasons were cited as key challenges in the enjoyment of health rights.				
Monitoring	**Actors**	**Comments**				
	Ministry of Health and Social Welfare					

Country: Madagascar						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	Section 19 provides for the right to healthcare: the State recognises and organizes for all individuals the right to the protection of health from their conception through the organization of free public health care, which gratuitousness results from the capacity of the national solidarity. Further provides support for the disabled in Section 30 which stipulates that: the State makes an effort to overcome the needs of every citizen who, for reason of their age or their physical or mental incompetence, find themselves in an incapacity to work, notably through the intervention of institutions or organs with a social character.	Law No. 2011-002 on the Health Code (*LOI n°2011-002 portant Code de la Santé*): provides social protections to persons with mental health illness and other NCDs. Provides that the list of diseases to which provisions on NCDs apply are determined by the regulations of the Minister of Health.	Health Sector Development Plan (*Plan National de Développement de Santé*)	Outdated. Recognises epilepsy as a specific mental health concern for priority intervention, in the same group as anxiety and sleep disorders, depression, psychosis and bipolar disorders. Then, separate from mental health issues like epilepsy, the other priority areas identified are disability (with examples including accident trauma and physical disability such as cerebral palsy) and NCDs such as cancer. A new plan was anticipated in March 2020. The status of this is unknown.	2015-2019	
			National Policy on Community Health, 2017 (*Politique Nationale de Sante Communautaire a Madagascar*)	Promotes public health through community decision making while health professionals are seen as resource persons. No mention of epilepsy but seeks to strengthen research in community health and determining the roles of "community agents" in dealing with NCDs.		
		Law No. 97-044 On Disabled People (*Loi N° 97-044 Sur Les Personnes Handicapées*): provides that every disabled person has the right to enjoy and benefit from medical services and specialised rehabilitation. Moreover, everyone with a disability has the right to quality physical and mental health care.	National Strategic Plan to Strengthen Community Health	Mentions that Community Agents have been trained in the prevention of NCDs and disability. Does not mention epilepsy.	2019 - 2030	

Country: Madagascar		
Implementation		**Summary of survey feedback** *No Data.*
Monitoring	**Actors**	**Comments**
	Ministry of Public Health	
	Health Committee (Comité de Santé)	Consists of Community Agents who operate at district level. It is the role of the Community Agents to anticipate any insufficiency or lack of management tools

Country: Malawi						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	On the aspect of health and as a principle of national policy, the Constitution provides that the State shall "actively promote the welfare and development of the people of Malawi by progressively adopting and implementing policies and legislation" to realise the right to healthcare and more specifically: "to provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care". Equality of opportunity to access health services is also listed as a necessary measure for the realisation of the constitutional right to development. An additional principle of national policy aims at enhancing the dignity and quality of life of persons with disabilities who are also expressly protected from discrimination.	Public Health Act, 1948: focuses on infectious diseases and has no mention of NCDs.	Health Sector Strategic Plan II	No mention of epilepsy as a specific area of concern but lists anti-epileptic medication as an intervention need in the category of NCDs. The guiding principles of the Health Sector Strategic Plan II include: the principle of primary healthcare, a human-rights based approach, equity, evidence based decision making as well as transparency and accountability.	2017-2022	
		Disability Act, 2012: contains provisions on the rights of persons with disabilities and includes the right to healthcare services (Section 6). Further, the Disability Act places a prohibition on discrimination in healthcare and rehabilitation services (Section 7). In terms of the Act, disability is defined as: a long-term physical, mental, intellectual or sensory impairment, which, in interaction with various barriers, may hinder the full and effective participation in society of a person on equal basis with other persons. Directs the Minister to establish the National Advisory Coordinating Committee on Disability Issues (NACCODI). (under review)	National Health Information System Policy, 2015	Seeks to ensure an adequate provision of information support to all stakeholders in the health sector for evidence-based decision making in the planning and management of health services		
			National disability mainstreaming strategy and implementation plan (NDMS&IP)	Outlines key areas to mainstream disability in public and private sector policies, plans, strategies and programmes- in line with other national and international policies and strategies. Includes epilepsy in its strategies and key activities. Establishes a national monitoring and evaluation framework and sets implementation modalities	2018 - 2023	

Country: Malawi		
Implementation	National disability mainstreaming strategy and implementation plan (NDMS&IP): assigns roles to various stakeholders namely, the 3 arms of government, NGOs, CSOs, faith-based organisations, academia, media, private sector, parastatals and the general public. Key indicators, baselines and targets have been identified for each sector in order to support reporting for monitoring and evaluation purposes.	**Summary of survey feedback** - Participants reported an underutilisation of laws and policies - The most pronounced obstacles towards the enjoyment of epilepsy health rights are: discrimination, unavailability of treatment, poor service provision including attitudes and perspectives of service providers, as well as personal sentiments i.e. people feel shy, embarrassed to claim their health rights and in so doing reveal their condition - There is an apparent lack of functioning monitoring and evaluation mechanisms despite the provisions for this in the National Disability Mainstreaming Strategy and Implementation Plan (NDMS&IP).
Monitoring	**Actors**	**Comments**
	National Advisory Coordinating Committee on Disability Issues (NACCODI)	The Disability Act states that this structure is to be established by the Minister to: *(a)* provide a forum for all key stakeholders on disability issues to receive, discuss and review reports from Government ministries and departments and other relevant stakeholders on disability mainstreaming; *(b)* make recommendations to Government on best practices regarding the formulation of policies, legislation and programmes, with respect to disability; and *(c)* oversee the implementation, monitoring and evaluation of disability-related programmes.
	Technical Working Group on Disability Mainstreaming (TWGDM)	Reviews reports on disability mainstreaming and makes recommendations to NACCODI for policy direction, resource mobilization and allocation
	Sector Working Groups on Disability Mainstreaming (SWGDM)	Main role in relation to disability mainstreaming is to coordinate planning, resource mobilization, implementation, monitoring and evaluation activities in each sector
	District Disability Mainstreaming, Monitoring and Evaluation Committee (DDMMEC)	The National Disability Mainstreaming Strategy directs that the DDMMEC should have a sub-committee on health
	Ministry of Gender, Children, Disability and Social Welfare	

Country: Mauritius						
	Constitution	**Legislation**	**Regulations & Policies**			**Epilepsy NAP**
					Validity	
Domestic legal and policy framework	No express provisions on the right to health or healthcare in the Constitution. Provisions on the protection of the right to life in Chapter 2, as a fundamental right (Sections 3(a) and 4).	Public Health Act 1925: primarily focuses on infectious diseases.	National Health Sector Strategic Plan	Only reference to epilepsy is in the context of "epileptic disorders" which are listed as psychiatric disorders.	2020-2024	
		Protection of Human Rights Act, 1998: establishes the National Human Rights Commission	National Policy Paper and Action Plan on Disability	Contains recommendations including on health which states that "persons suffering from chronic mental illnesses and intellectual disabilities should be provided with special support and health assistance" by the State.		
		Training and Employment of Disabled Persons Act 1996: also referred to as the "Disability Act": defines disability as to have a long-term physical disfigurement or physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to barriers or prejudices impeding his participation at an equal level with other members of society in major life activities, undertakings or fields of employment that are open to other members of society	Special Education Needs and Inclusive Education Policy and Strategy Document	Aimed at children between the ages of 0-18. Mentions epilepsy as one of the disabilities which are classified by the Ministry of Social Security as constituting special education needs in children.		
		Equal Opportunities Act 2008: The Act provides protections to persons with impairments, particularly against employment discrimination. Further defines impairment as				

Country: Mauritius				
		inclusive of malfunction of a part of the body, including – (i) a mental or psychological disease or disorder; (ii) a condition or disorder that results in a person learning more slowly than people who do not have that condition or disorder.		
Implementation		**Summary of survey feedback** - "The Disability Act" is the most inclusive legal instrument which persons with epilepsy may rely on by virtue of the definition of disability provided in the Act which refers to physical disfigurement or physical, mental or sensory disability. Notably this Act was designed specifically to cover the training and employment of persons with disabilities.		
Monitoring	**Actors**	**Comments**		
	Ministry of Health and Wellness			
	National Health Accounts & National Health Observatory			
	Ministry of Social Security, National Solidarity and Institutional Reform			
	Equal Opportunities Commission	Independent statutory body to administer the Equal Opportunities Act		
	National Human Rights Commission	Investigates complaints related to the human rights enshrined in Chapter 2 of the Constitution which have been violated or are likely to be violated by the act or omission of a public officer or employee of a public body, or complaints related to any act or omission by a member of the police. Chapter 2 does not include the right to health but does have a provision on the right to life.		
	National Council for the Rehabilitation of Disabled Persons (NCRD)	Established by Section 4 of the NCRD Act 1986		

Country: Mozambique						
	Constitution	**Legislation**	**Regulations & Policies**			**Epilepsy NAP**
					Validity	
Domestic legal and policy framework	Section 89 provides that: all citizens shall have the right to medical and health care, within the terms of the law, and shall have the duty to promote and protect public health. On the social organisation of health: Section 116 states that: 1. Medical and health care for citizens shall be organised through a national health system, which shall benefit all Mozambican people. 2. To achieve the goals of the national health system, the law shall establish the ways in which medical and health care is delivered. 3. The State shall encourage citizens and institutions to participate in raising the standard of health in the community. 4. The State shall promote the expansion of medical and health care and the equal access of all citizens to the enjoyment of this right. 5. The State shall be responsible for promoting, supervising and controlling the production, the sale and the use of chemical, biological and pharmaceutical products and other forms of treatment and diagnosis. 6. The medical and health care activities run by collective and private entities shall be carried out in accordance with the law and be subject to the supervision of the State.	Social Protection Law (4/2007)	National Strategy for Basic Social Security, 2010			
			Mental Health Strategy and Action Plan (*Estratégia e Plano de Acção para a Saúde Mental*)	Highlights epidemiological surveillance and operational research on epilepsy as action areas and further aims to implement prevention activities with regards to epilepsy	2016-2026	
			Strategic Plan for the Health Sector	Outdated. Mentions, as part of the envisaged strategic interventions for mental health, that epilepsy is an area in which there is need to conduct research on prevalence, knowledge, attitudes and practices. Epilepsy is not mentioned in other contexts.	2014-2019	
			National Action Plan for Disabilities	Outdated. Does not mention epilepsy but lists mental health as a leading cause of disability. The NAP for Disabilities also aims to ensure rehabilitation, medical and drug assistance for people with mental disabilities	2012-2019	
		Summary of survey feedback				

Country: Mozambique		
		- There are limited references to epilepsy in laws and action plans - The promotion of health policy objectives, such as universal health coverage, the right to the highest possible standard of treatment for epilepsy, as well as access to quality health care and training are deemed challenges as far as health laws in Mozambique are concerned - Furthermore, persons with epilepsy report discrimination, cultural and religious beliefs and the unavailability of treatment as major issues hindering the enjoyment of health rights for persons with epilepsy
Monitoring	**Actors**	**Comments**
	National Health Institute	
	MISAU (Ministry of Health)	

Country: Namibia						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	There is no express provision on the right to health in Constitution however, Section 95 stipulates that the State shall actively promote and maintain the welfare of the people by adopting, inter alia, policies aimed at consistent planning…to improve public health.	Mental Health Act: defines mental illness as: any disorder or disability of the mind, and includes any mental disease, any arrested or incomplete development of the mind and any psychopathic disorder, and "mentally ill" has a corresponding meaning. The Act is under review.	National Health Policy Framework	Outdated. Addresses mental health and disability and lists strategic response directions which include the integration of mental health care into primary healthcare systems.	2010-2020	
			National Policy for Mental Health, 2005	Refers to epilepsy as an example of a mental disorder together with psychosis and depression.		
		Health Act, 2015: disability is mentioned once in the Act in the context of admission as a State or private patient in which circumstance the consent of a guardian must be obtained if the patient has a legal disability. References to mental illness in the Act are made only as grounds for removal from office of administrative health officials and as a research area which may be authorised or commissioned by the Minister of Health.	National Policy on Disability, 1997	Under a review process which according to the Deputy Minister during the 12th Session Of The Conference Of State Parties To The Convention On The Rights Of Persons With Disabilities (2019) was prompted by an effort to meet both its domestic and international obligations through the use of stronger textual language in the domestic institutional, policy and legislative framework that will reflect the letter and spirit of the CRPD.		
		National Disability Council Act, 2004: defines disability as a physical, mental or sensory impairment that alone, or in combination with social or environmental barriers, affects the ability of the person concerned to take part in educational, vocational,				

Country: Namibia				
		or recreational activities.		
Implementation		**Summary of survey feedback** *No Data*		
Monitoring	**Actors**	**Comments**		
	Directorate of Social Services in the Ministry of Health and Social Services			
	The Division of Disability Prevention and Rehabilitation			
	National Disability Council	Established by National Disability Council Act, 2004. Its functions include monitoring the implementation of the National Policy on Disability and to identify provisions in any law, which may hinder the implementation of the National Policy on Disability.		

Country: Nigeria						
Domestic legal and policy framework	**Constitution**	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
	Other than the provision which stipulates that the State shall direct its policy towards ensuring that, amongst other agendas, there are adequate medical and health facilities for all persons, there is no explicit right to health under the Constitution. Furthermore, the above provision is situated in Chapter 2 of the Constitution which according to its Section 6, all aspects contained therein (Chapter 2) are non-justiciable. Consequently, there can be no judicial adjudication against the State pertaining to the realisation of this provision should the need so arise.	National Health Act 2014: explains the national health system which operates on federal and state levels. Therefore, there is a Federal Republic Ministry of Health (national) and each of the 36 States plus the Federal Capital Territory (FCT), in principal, has a ministry of health.	National Policy and Strategic Plan of Action on Prevention and Control of NCDs, 2013	Addresses mental, neurological and substance use disorders as target areas. Refers to "seizure disorders" as common in Nigeria but does not expressly classify this as either a mental or neurological disorder.		
			National Policy on Special Needs Education	Does not mention epilepsy in its explanation of who are considered persons with disabilities, but, refers to seizures as an example of "physical and health" impairment together with cerebral palsy, paraplegia and quadriplegia.		
		Discrimination against Persons with Disabilities (prohibition) Act 2018: establishes the National Commission for Persons with Disabilities and prohibits and penalises discrimination against persons with disabilities				
		Lunacy Ordinance, 1958: the only current mental health legislation in force. It classifies mental illness as lunacy.				

Country: Nigeria		
Implementation		**Summary of survey feedback** -The greatest obstacles to the enjoyment of health rights for persons with epilepsy were identified as: discrimination, the unavailability of treatment, the cost of treatment, as well as poor service provision including attitudes and perspectives of service providers -Though there is no official mention of epilepsy in legislative texts, survey responses show that epilepsy in Nigeria is regarded as a mental health issue. As such, this assumption places persons with epilepsy as potentially subject to the archaic Lunacy Ordinance which defines mental illness as lunacy. The Lunacy Ordinance has drawn criticism from various sectors for its use of demeaning language and the restrictive connotations which diminish the capacity for self-determination for some persons with conditions classified as mental health illnesses.
Monitoring	**Actors**	**Comments**
	National Commission for Persons with Disabilities	Executive Members appointed in 2020. Derives mandate from the Discrimination against Persons with Disabilities (prohibition) Act of 2018.

Country: Rwanda						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	Provides for the right to good health (Section 21) and Section 45 places the burden on the State to mobilise the population for activities aimed at good health and to assist them in the realisation of those activities.	Law Nº 01/2007 Of 20/01/2007 On The Protection Of Disabled Persons: Defines disability as "the condition of a person who has lost the skills essential to life or failing in relation to other people and therefore not enjoying chances equal to those of others". Additionally, "a disabled person is any person presenting a congenital defect or failure acquired as a result of illness, accident, conflict or other causes that may cause a handicap".	Disability Mainstreaming Guidelines, 2014	Discusses disability mainstreaming in health care		
			Health Sector Policy, 2015	In its policy directions, care for epilepsy is mentioned as a mental health concern for priority intervention with the overall aim of integrating mental health into primary healthcare systems.		
			Mental Health Policy, 2011	An explicit objective of this policy is to initiate an exact strategy of intervention and care specific to epilepsy (pg. 7). Epilepsy treatment is singled out as a field of intervention and strategies include community mobilisation and establishing a technically skilled reference structure in epileptology. The policy also aims to eradicate stigmatisation and marginalisation of persons with mental health concerns. On the aspect of legislation, the Mental Health Policy sets targeted objectives to develop a patient-centred legal framework and to define a framework that mitigates abuses in mental health practice by clarifying limitations in each intervention.		

Country: Rwanda						
			National Community Health Policy, 2015	Implementation seeks to strengthen the decentralisation of health services and structures down to the district level and villages. Does not acknowledge mental health specifically although NCDs and children with disabilities are mentioned as areas of concern.		
			NCD Policy, 2015	In this policy epilepsy is mentioned as a risk-factor for certain NCDs. The Executive Summary states that: "non-traditional risk factors for endemic diseases linked to infection e.g. …*some cases of epilepsy*… play a significant role in spreading NCDs". This appears to suggest that some cases of epilepsy are risk factors linked to infection for diseases that are endemic to a population and play a significant role in **spreading non-communicable diseases.** Elsewhere, injuries and disabilities are given as examples of NCDs which the policy focuses on.		
Implementation		**Summary of survey feedback** *No Data*				
Monitoring	**Actors**	**Comments**				
	National Council of Persons with Disabilities					
	Mental Health Division, Ministry of Health	Ensures implementation of mental health policy				

Country: Seychelles

	Constitution	Legislation	Regulations & Policies		Validity	Epilepsy NAP
Domestic legal and policy framework	Section 29: "the State recognises the right of every citizen to protection of health and to the enjoyment of attainable standard of physical and mental health and with a view to ensuring the effective exercise of this right the State undertakes- a. to take steps to provide for free primary health care in State institutions for all its citizens. b. to take appropriate measures to prevent, treat and control epidemic and other diseases;. c. to take steps to reduce infant mortality and promote the healthy development of the of the child; d. to promote individual responsibility in health matters; and e. to allow, subject to such supervision and conditions as are necessary in a democratic society, for the establishment of private medical services." Section 36: "the State recognises the right of the aged and the disabled to special protection and with a view to ensuring the effective exercise of this right undertakes- … a. to make reasonable provision for improving the quality of life and for the welfare and maintenance of the …disabled".	Public Health Act, 2015: deals solely with infectious diseases. Public Health Authority Act, 2013 National Council for Disabled Persons Act, 1994 defines a disabled person as a person suffering from a physical or mental disability on account of injury, disease or congenital deformity Mental Health Care Act, 2020 defines mental illness as a substantial disorder of thinking, mood, perception, orientation or memory that impairs judgment, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, including mental conditions associated with alcohol and drugs but does not include solely intellectual disability. Further sets out the rights of persons with mental illness.	National Health Strategic Plan (NHSP)	Outdated. In its assessment of the contribution of different risk factors to different causes of death or injury, mental disorders and neurological disorders are named but the Plan does not define these. Over 30 diseases and conditions are individually recognised in the NHSP and epilepsy is not among these.	2016-2020	
			Strategy for the Prevention and Control of Non-Communicable Diseases	Although the Strategy recognises that other NCDs such as neurological diseases, mental disorders and disabilities contribute to the burden of NCDs in the Seychelles, it emphasises that the main focus is on cardiovascular diseases, cancer, chronic respiratory diseases and diabetes as well as their common behavioural risk factors.	2016-2025	
			National Health Policy	The National Health Policy defines the vision of the health sector as "the attainment, by all people in Seychelles, of the highest level of physical, social, mental and spiritual health and	2016-2025	

Country: Seychelles						
				living in harmony with nature". Highlights that the burden of disease in the country is in NCDs, injuries, and mental health problems. Epilepsy is not mentioned in this policy document		
Implementation		**Summary of survey feedback** *No data.*				
Monitoring	**Actors**	**Comments**				
	Public Health Authority	Established by the Public Health Authority Act, 2013 to monitor all health programmes amongst other functions				
	National Council for Disabled Persons	Established by the National Council for Disabled Persons Act, 1994				

Country: Sierra Leone						
Domestic legal and policy framework	**Constitution**	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
	Section 8 provides that the State is obliged as part of its social objectives to direct its policy so that it ensures there are adequate medical and health facilities for all persons, having due regard to the resources of the State and that the care and welfare of the disabled are actively promoted and safeguarded.	Persons with Disability Act, 2011: defines disability as a physical, sensory, mental or other impairment which has a substantial long-term adverse effect on a person's ability to carry out normal day-to-day activities.	Mental Health Policy	Outdated. Lists epilepsy as an example of a neurological condition within the framework of mental health conditions.	2010-2015	
		Lunacy Act, 1902: the only current legislation which governs issues of mental health. The Act is under review.	National NCD Strategic Plan	Outdated. The stated goal of the NCD Strategic Plan is to reduce the burden of NCDs including mental disorders and NCDs. Recognises epilepsy as a growing NCD concern.	2013-2017	
Implementation		**Summary of survey feedback** *No Data.*				
Monitoring	**Actors**	**Comments**				
	NCD Technical Working Group					

Country: South Africa						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	Section 27 guarantees everyone the right to access healthcare services and places the onus on the State to adopt reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of this right. The rights to equality, dignity and life are extended to all persons. The Constitution has a list of non-derogable rights from which there can be no exceptions. The right to equality is non-derogable solely in respect of unfair discrimination on the grounds of race, colour, ethnic or social origin, sex, religion or language. Disability is not mentioned in this regard whereas it appears in the section on equality. The rights to human dignity and life are non-derogable in their entirety.	National Health Act, 2003: establishes a national health system which protects, respects, promotes and fulfils the rights of vulnerable groups such as persons with disabilities, addresses the protection of health records, establishes the National Health Council and directs that the general functions of the National Health Department include the provision of mental healthcare services,	National Disability Policy	Defines disability as the result of a moderate to severe limitation to a person with physical, sensory, communication, intellectual or mental impairment, to function /or to perform daily activities as a result of limitations/barriers which may be due to economic, physical, social, attitudinal and/or cultural factors.		Draft policy reported to be under review.
		Promotion of Equality and Prevention of Unfair Discrimination Act, 2000: emphasises the constitutional prohibition against discrimination on grounds of disability and presents an illustrative list of unfair practices in certain sectors which includes failing to make healthcare facilities available to any person	White Paper on the Rights of Persons with Disabilities	Broad statement of government policy which recognises that the notion of disability is a complex and evolving concept. Includes those who have perceived and or actual physical, psychosocial, intellectual, neurological and/or sensory impairments which, as a result of various attitudinal, communication, physical and information barriers, are hindered in participating fully and effectively in society on an equal basis with others.		
		Mental Health Care Act, 2002: defines mental illness as a positive diagnosis of a mental health related illness in terms of diagnostic criteria made by a mental health care practitioner authorised to make such diagnosis.	Department of Health Strategic Plan	Considers mental disorders as NCDs which are a priority area but does not specifically mention epilepsy. Mental disorders are not defined.	2020/21 - 2024/25	

Country: South Africa						
			National Mental Health Policy Framework and Strategic Plan	Priorities are (i) improving detection rates and management of mental disorders especially in primary health care settings; (ii) improving mental health infrastructure capacity especially at community level; and (iii) improving the supply of and access to mental health professionals	2013-2020	
Implementation		**Summary of survey feedback** - The country has a strong human rights approach to legislation and policy development. - However, legislation and policies are excellent on paper but fail in implementation. - Obstacles to the enjoyment of health rights for persons with epilepsy include: unavailability of treatment, lack of information / knowledge, cost of treatment, costs related to accessing service providers i.e. travelling expenses, consultation fees, and poor service provision including attitudes and perspectives of service providers - Epilepsy in South Africa is viewed as a disability and thus persons with epilepsy, in principle, enjoy the same standing in legislation as those with other disabilities.				
Monitoring	**Actors**	**Comments**				
	Department of Health					
	Department of Women, Youth & Persons with Disabilities					
	South African Human Rights Commission					
	National Disability Rights Coordinating Mechanism	Primarily responsible for overall coordination of implementation and monitoring of the national disability rights agenda				
	Department of Social Development					

Country: Tanzania						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	There is no express constitutional provision regarding the right to health. Section 11 however does articulate the State's obligation to make appropriate provisions for social welfare at times of sickness or disability and in other cases of incapacity.	Persons with Disabilities Act, 2010: defines disability as loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors. Further defines mental disability as the inability to meet individual and societal needs by reason of emotional and mental retardation;	National Policy on Disability	Addresses mental health and persons with disabilities, the latter in the context of HIV/AIDS response. Disability is defined as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors. Does not define or give examples of mental health issues.		
		The Persons with Disabilities (Rights and Privileges), 2006 – Zanzibar. Applies to the territory of Zanzibar. Adopts a broad definition of disability that includes neurological impairments, conditions and health needs.	National Health Policy, 2017	The policy objective of this document is to reduce morbidity, disability and mortality due to non-communicable diseases. Discusses main NCDs which include mental health and in a brief synopsis on other NCDs mentions brain and neurological diseases. Does not mention epilepsy.		
		Public Health Act, 2009: regulates infectious diseases primarily as well as epidemic, endemic, and pandemic diseases which are specified. Does not address mental or neurologic disorders.	NCD Strategic Plan	Outdated. Suggests that because the health sector is over stretched, there is a tendency in public health facilities to neglect common mental disorders and focus is instead placed on severe mental illnesses and epilepsy. No other reference to epilepsy is made.	2016-2020	
		Mental Health Act, 2008: primarily procedural and does not define mental illness or mental health disorders.				

Country: Tanzania		
Implementation		**Summary of survey feedback** *No Data.*
Monitoring	**Actors**	**Comments**
	Ministry of Health, Community Development, Gender, Elderly and Children	

Country: Zambia						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	No direct provision on the right to health. Section 11 of the Bill of Rights (Part 3 of the Constitution) protects the right to life.	The Persons with Disabilities Act, 2012: prohibits discrimination against persons with disabilities. Defines disability as a permanent physical, mental, intellectual or sensory impairment that alone, or in a combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others.	National Health Policy (NHP), 2011	In a discussion on NCDs, the NHP provides a list of life style-oriented health problems which includes epilepsy, mental illnesses and trauma.		
			National Policy on Disability, 2013	Specific framework for addressing disability issues in Zambia		
			NCD Strategic Plan	Outdated. Recognised the prevalence of epilepsy as a stand-alone disease (NCD). Responses included strengthening the prevention of epilepsy and other seizure disorders, through scaling up of awareness and education on the causes of these health problems.	2013-2016	
		Mental Health Act, 2019: protects and promotes the rights of persons with mental illness, mental disorder, mental impairment or mental disability and defines mental disorder as a diagnosis of a mental condition, impairment or disability in the absence of demonstrable organic etiological factor also referred to as functional neurosis or psychosis. Whereas mental illness is defined as means a mental impairment or disability with evidence of an organic aetiology and mental impairment is a permanent outcome, effect, aftermath or after effect of a mental				

Country: Zambia					
		illness that affects a person's ability to function normally in society			
		Public Health Act, 2006: addresses communicable / infectious diseases. Does not cover disabilities or mention mental health issues outside of a reference to vaccination of "inmates" in mental hospitals.			
Implementation	National Disability Policy Implementation Framework outlines the roles and responsibilities of key stakeholders and includes monitoring and evaluation functions.	**Summary of survey feedback** -It was reported that legislative policy makers do not understand the health system. It is thus difficult for them to prioritise certain aspects such as epilepsy within the context of their limited understanding of the health system. - Obstacles to the enjoyment of health rights for persons with epilepsy were recorded as: -discrimination, unavailability of treatment, -lack of information / knowledge, -costs related to accessing service providers i.e. travelling expenses, consultation fees, -poor service provision including attitudes and perspectives of service providers, -personal sentiments i.e. people feel shy, embarrassed to claim their health rights and in so doing reveal their condition, -attitudes and perspectives of home care givers i.e. family is not concerned; as well as -cultural and religious reasons. -Poor engagement between epilepsy organisations and government is observed. As such, there continue to be gaps in the provision of health services for persons with epilepsy such as the absence of clear policy		
Monitoring	**Actors**	**Comments**			
	Health Professionals and Parliamentary Health Committee				
	NCDs Unit				
	Zambia Agency for Persons with Disabilities	Functions include planning, promoting and administering services for persons with disabilities as well as monitoring and evaluating the provision of services to persons with disabilities			
	National Mental Health Council				

Country: Zimbabwe						
	Constitution	**Legislation**	**Regulations & Policies**		Validity	**Epilepsy NAP**
Domestic legal and policy framework	The Constitution mandates the State in its national objectives to take all practical measures to ensure the provision of basic, accessible and adequate health services throughout Zimbabwe (Section 29). Further to this provision, the right to health care, including persons with chronic illnesses, is articulated in Section 76 which applies to every citizen and permanent resident. The specific provisions state: "every citizen and permanent resident of Zimbabwe has the right to have access to basic health-care services, including reproductive health-care services... Every person living with a chronic illness has the right to have access to basic healthcare services for the illness". On persons with disabilities, the national objectives in the Constitution provide that: the State and all institutions and agencies of government at every level must recognise the rights of persons with physical or mental disabilities, in particular their right to be treated with respect and dignity. On the specific rights of persons with disabilities the Constitution states, within the limits of the resources available, the State must implement fitting measures to ensure that persons with disabilities realise their full mental and physical potential including giving them access to medical, psychological and functional treatment.	Public Health Act, 2018: guides the control of infectious diseases and NCDs. On NCDs, the Minister is empowered to declare any disease or condition as an NCD of public health importance and in respect of that disease or condition, prescribe special measures to prevent and control the NCD.	National Disability Policy, 2021	Adopted by Cabinet in February 2021. The policy seeks to address the marginalisation and discrimination of Persons with Disabilities		
		Disabled Persons Act: defines a disabled person as a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society;	National Health Strategy	Outdated. Lists epilepsy as a common NCD – distinctively from mental illness but still as a mental health concern. Improving epilepsy management is identified as a specific objective	2016-2020	
		Mental Health Act: defines the terms "mentally disordered or intellectually handicapped", as occurring in relation to any person, means that the person is suffering from mental illness, arrested or incomplete development of mind, psychopathic disorder or any other disorder or disability of the mind.	National Strategic Plan for Mental Health Services	Only acknowledges that epilepsy is a priority condition in the WHO mhGAP. Suggests that neurological disorders fall within the scope of mental health and thus the Strategic Plan is applicable to all neurological disorders.	2019-2023	
			Mental Health Policy	Provides a framework for designing, implementing, monitoring and evaluating mental health programmes within the context of decentralised primary healthcare.		

Country: Zimbabwe		
Implementation		**Summary of survey feedback** - The main obstacles to enjoying the right to health for persons with epilepsy which were highlighted are: unavailability of treatment, cost of treatment, costs related to accessing service providers i.e. travelling expenses, consultation fees as well as poor service provision including attitudes and perspectives of service providers
Monitoring	**Actors**	**Comments**
	National Disability Board	
	Ministry of Health and Child Welfare	

Concluding remarks

Many of the African States studied have adopted, in a myriad of ways, a blanket approach towards covering epilepsy through NCDs, mental health issues and disability health laws and policies. But, the absence of specific national action plans and the non-recognition of epilepsy in so many key laws and strategies which expressly recognise other NCDs, adds to the challenges experienced by the millions of people with epilepsy on the continent. From the overview of international and regional legal instruments which affect the health rights of individuals in this report, it can be observed that certain instruments are very specific to the health rights of particular groups. These instruments are additionally attached to related monitoring and reporting mechanisms. Consequently, it is very important for the adoption of cohesive terminology and classification of epilepsy at domestic level.

Moreover, it is imperative for antiquated legislative provisions to be reviewed and either abolished in their entirety or amended to align with more progressive rights-based and evidence-based laws and policies. The mainstreaming of disability policies in various sectors should be articulate in the consideration of conditions that are highly stigmatised such as epilepsy. Such an approach is necessitated by the alarming marginalisation of persons with epilepsy, bearing in mind that the stigma, discrimination and spiritual beliefs that are associated with epilepsy in the African context undoubtedly result in under-reporting of statistics and experiences.

While it is anticipated that progress towards the development of a global action plan on epilepsy is imminent, it is questionable whether African States that have not at their national level began to acknowledge epilepsy as a pressing health concern, could make significant and domestically translatable contributions to such global action plan. The negative outcome thereof being the risk that another international commitment on epilepsy fails to live up to the hopes of those affected.

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