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ESR Review

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The overarching challenge faced by persons with albinism is long-term neglect of the issue, resulting in the absence of their voice in the public sphere. Also, a significant number of persons with albinism globally are not aware of the laws that protect them and continue to linger in various forms of suffering and neglect. Efforts need to be made to build their capacity (particularly that of civil society leaders and advocates) on the norms and standards of human rights and also on the human rights approach.

Ikponwosa Ero

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From the editor:

This is the second edition of the ESR Review for 2017. It includes a feature article on sanitation and an interview with the UN Independent Expert on the rights of persons with Albinism.

The feature article by Pedi Obani discusses the link between the National Policy on Health 2016 and the right to sanitation in Nigeria. She argues that the Policy presents a great opportunity for the Nigerian government to make the link between the health of the population and the right to sanitation. According to her, 'sanitation and hygiene services are pivotal for universal health coverage in Nigeria'. She then critically reviews the provisions of the Policy and concludes that they make a conscious effort in linking health services with sanitation, however, lumping the rights to water and sanitation together is problematic and may lead to the side-lining of the latter.

The interview with the UN Independent Expert on the rights of persons with albinism, Ikponwosa Ero reveals the various challenges facing persons with albinism across the world, particularly in Africa. According to the Independent expert, discrimination and superstitions continue to fuel human rights abuses of persons with albinism in many African countries. She then discusses the various strategies to address human rights violations experienced by persons with albinism in Africa.

This edition of the Review also contains reports from two workshops as well as updates from the UN human rights system. We hope you will enjoy reading it.

Ebenezer Durojaye

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The National Health Policy 2016: A Missed Opportunity for Advancing the Human Right to Sanitation for Nigerians?

by **Pedi Obani**

Introduction

Universal health coverage requires a broad focus not only on health-care settings and professionals but on related rights, infrastructure and services – such as sanitation – that can affect public health outcomes directly or indirectly. The synergy between universal health coverage and the human right to sanitation cuts across the public health promotion, disease prevention, and curative and rehabilitation dimensions of health services. For instance, public health promotion services can be an effective means of spreading information about the human right to sanitation and institutionalising mechanisms for access to information about sanitation services, remedies and accountability. Similarly, disease prevention can be strengthened through universal access to safe, accessible, acceptable, affordable and adequate sanitation services, including the safe collection, treatment and disposal of wastewater and health-care waste; curative services can be more effective when people within the healthcare setting are protected from disease vectors like mosquitoes and provided with safe access to sanitation and drinking-water facilities; rehabilitative and palliative services are enhanced when people who are either treating or managing various kinds of ailment or disability have access to basic necessities tailored to meet special needs they may have.

The National Health Policy 2016 indicates that Nigeria is currently far from the mark in attaining universal health coverage in terms of public health promotion, disease prevention, and curative and rehabilitation services. Although the country has recorded progress in some of its health indicators (such as under-five and infant mortality rates) and was among the countries that successfully contained the Ebola virus disease during the international health emergency in 2014, other health indicators such as maternal health suggest it is making slow progress. In this regard, Nigeria has a high prevalence of communicable diseases. These account for about 66 per cent of total morbidity, a situation exacerbated by poor sanitation and hygiene practices (Federal Ministry of Health, 2016). To put it differently, sanitation and hygiene services are pivotal for universal health coverage in Nigeria, and the focus this paper is on the prospects that the current Policy holds for advancing the human right to sanitation.

The Policy is the third national health policy for Nigeria, with the first two such policies having been introduced in 1988 and 2004, respectively. Formulated in order to promote universal health coverage for accelerated socio-economic development, the Policy comes at an especially opportune time, given that it follows in the wake of a global commitment to achieving the Sustainable Development Goals (SDG) by 2030. The SDGs include goals regarding health as well as water and sanitation, which underlines the growing

recognition of sanitation as an independent right critical for the realisation of numerous other related social, economic and cultural human rights, among them the right to health.

In the sections below, I first highlight the institutional barriers to realising the human right to sanitation. Next, I analyse the coverage of sanitation within the Policy Objectives and Orientations in Chapter 4 of the Policy, showing how it falls short of promoting universal access to sanitation; this serve as a precursor to the concluding thoughts presented in the final section.

Institutional barriers to realising the human right to sanitation

Despite the increasing momentum that the human right to sanitation has gathered in recent years, the level of access to sanitation in Nigeria remains deplorable. About 30 per cent of households use improved toilets, 25 per cent of them use shared toilet facilities, 45 per cent use unimproved toilet facilities, and 29 per cent resort to open defecation (Federal Ministry of Health, 2016). Access to sewerage management and other waste management services is also limited (Federal Ministry of Health, 2016). The poor status of sanitation coverage is the result of a number of institutional barriers, which include an emphasis on individual responsibility; fragmented leadership from state departments and agencies; inequitable allocation of resources for sanitation; and the non-justiciability of socio-economic rights.

First, sanitation is viewed in the main as the responsibility primarily of households and individuals. To this end, national sanitation policies over the years have emphasised the need for community, including individual, ownership and management of on-site sanitation (Federal Ministry of Water Resources, 2000; 2004). However, the absence of technical and financial support for the very poor and other vulnerable groups that may not be able to afford the cost of sanitation, coupled with inadequate regulation to ensure compliance with safety standards for facilities as specified in the legal framework, means that individuals and communities cannot be expected to deliver the human right to sanitation.

This negates the character of sanitation as a public good, one that requires universal access in order to minimise negative externalities from non-users (Mader, 2012). In addition, sanitation is a merit good which requires the intervention of the state to counter inherent tendencies for preference distortion that may hamper private investments in safe sanitation options and instead make unsafe practices like open defecation more attractive in some contexts (Mader, 2012).

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Secondly, fragmented leadership or responsibility for sanitation compounds the sanitation problem (Federal Ministry of Water Resources, 2000). The National Sanitation Task Group and State Sanitation Task Groups are made up of the key stakeholders working in the sanitation sector at the national and state levels, respectively, but there is a lack of clarity about their roles and poor delivery of sanitation services is still a problem, particularly in the urban centres.

Urban sanitation is especially problematic because the responsibility for the delivery of sanitation services in urban areas is divided among a variety of departments and ministries dealing with, inter alia, the environment, health, water resources, agriculture, education, women's affairs and social development, yet with minimal coordination of their respective sanitation policies and programmes. At the same time, communities and individuals provide their own sanitation services within their homes and in public places under their control (business centres, for instance), with little regulation of technical and safety standards. This often creates public health risks as a result of unsafe practices such as the disposal of raw sewage in water bodies.

Thirdly, the predominant approach that public health authorities take to sanitation programming and intervention is one aimed at transforming the latent demand for sanitation services into a strong demand for services which is both visible and backed by the willingness to pay. However, the approach is limited in its effectiveness owing to the underlying motivations of the public and the disincentives that prevent people from accessing sanitation.

Sanitation is a basic necessity for human survival and environmental sustainability, but the demand for sanitation services may appear to be latent, where

(a) sanitation services are designed within a technocratic paradigm rather than being tailored to address the pre-existing needs of vulnerable and marginalised groups who are excluded from the sanitation governance process;

(b) taboos result in the exclusion of minorities from demanding or accessing sanitation services, or in other ways encourage unsanitary practices;

(c) insecurity of tenure hampers the willingness of households and individuals to make the necessary capital investment in sanitation infrastructure;

(d) poverty constrains the ability to afford the cost of sanitation infrastructure or connection and maintenance fees; or

(e) local environmental conditions affect the viability of certain pre-designed sanitation technologies.

With regard to the public, there is evidence that the motivations for using sanitation services are often more closely linked to dignity, physical security, privacy, convenience and affordability than an overriding concern for health benefits (Joshi et al., 2011; Seraj, 2008).

These factors may likewise affect the extent to which people are willing to pay for sanitation services. Hence, sanitation interventions ought to respond to the motivations and needs of the public in order to be effective in triggering demand and willingness to pay.

Nonetheless, even so there may still be poor people who cannot afford the cost of basic sanitation services and therefore require financial assistance if universal coverage is to be ensured.

Fourth, the limited public resources allocated for the expansion of sanitation services are often expended on formal settlements to the exclusion of informal ones. The available resources for regulation and enforcement are also concentrated within formal settlements and do not benefit the poorest and most vulnerable populations that are kept invisible outside the city. This occurs, for instance, when formal settlements are prioritised over informal settlements for the delivery of state-subsidised waste management services, with the result that the latter are excluded from the service network. Ironically, formal settlements are often inhabited by residents who are relatively more affluent, can probably afford at least the cost of basic sanitation services and therefore are already enjoying a higher level of sanitation coverage than people in informal settlements. Hence, policies that subsidise sanitation services in formal settlements to the exclusion of informal ones inadvertently exacerbate the inequities in access to sanitation and thereby pose a risk to public health outcomes for society as a whole.

Such policies also fuel distrust between the state and residents of informal settlements, with the latter being further sanctioned by the state for, inter alia, their poor sanitary practices. Conversely, public health promotion programmes disseminated in local languages and public places like markets and motor parks are capable of reaching large audiences and improving relational inclusion.

Fifth, socio-economic rights are *stricto sensu* not justiciable in Nigeria, except where they are legislated upon (Fagbohun, 2010; Popoola, 2010). Nonetheless, Nigeria voted in favour of the United Nations General Assembly (UNGA) Resolution A/64/292 of 3 August 2010, on the human right to water and sanitation. The Resolution is indeed one of the main international law instruments that heralded the evolution of the human right to sanitation as an independent right; the latter's emerging status in international law is supported by *opinio juris* and various practices among states in Nigeria, including the integration of human rights principles in the formulation of the SDG sanitation goal and targets. Furthermore, the human right to sanitation is critical to the realisation of fundamental rights contained in the country's 1999 Constitution, among them the right to life, as well as the human and peoples' rights in the African Charter on Human and Peoples Rights (the Charter). The Charter rights have been domesticated in Nigeria through the African Charter on Human and Peoples' Rights (Ratification and Enforcement) Act 1983.

Thus, the human right to sanitation imposes obligations on the Nigerian government to ensure that public utilities and non-state actors involved in the delivery of sanitation services respect, protect and fulfil the right. This duty is not diminished by the lack of express recognition of the human right to sanitation under the 1999 Constitution.

Coverage of sanitation in the National Health Policy

The Policy contains a combined water and sanitation goal under the section on health-related problems and issues. The goal, which is to 'reduce the disease burden resulting from unsafe drinking water and poor sanitation', is linked furthermore to the objective of promoting 'universal access to safe drinking water and acceptable sanitation' (Federal Ministry of Health, 2016). The four policy orientations or initiatives regarding water and

and sanitation are to

(a) promote the provision of adequate and safe water and appropriate sanitary facilities in urban and rural areas through multi-sectoral collaboration, public-private partnerships and effective community engagement’;

(b) develop and implement quality standards for safe potable drinking water’;

(c) develop and implement National Framework for Water Quality Monitoring and Surveillance strategies’; and

(d) promote awareness on the risks linked with consumption of unwholesome water’ (Federal Ministry of Health, 2016).

There are arguments both for and against the linking of water and sanitation in the engineering, development and human rights fields (Ellis and Feris, 2014). However, looking at the Policy and the Nigerian context, there appears to be a stronger case for de-linking water and sanitation, and for at least two reasons.

To start with, combining the water and sanitation goal in the Policy already increases the likelihood that sanitation will be side-lined and more focus placed on water. This is already evident from the four policy orientations or initiatives, which tilt towards ensuring universal access to safe drinking water without creating much room for developing strong initiatives for acceptable sanitation. It is also not clear whether the policy orientation or initiative to promote ‘appropriate sanitary facilities’ pertains to the actual provision of sanitation infrastructure such as toilets, sewerage treatment plants, and hand-washing facilities, or to maintaining sanitation and hygiene levels in health facilities, for instance. Secondly, the combination of the water and sanitation goal is influenced by a predominantly technocratic approach and ignores the fact that the motivations for sanitation are much broader than those to do with concerns about water quality: this is one of the institutional barriers to universal access to sanitation. Conversely, there are dry sanitation systems which may also pose a contamination risk to land and environmental resources other than water quality per se.

The Policy’s goal, objective, and orientations or initiatives do not adequately reflect the content of the human right to sanitation, which includes safety, accessibility, acceptability and affordability. Although the formal recognition of a human right is no magic wand for addressing a myriad of human development challenges, the content of the human right to sanitation offers inadequate framework for addressing the institutional barriers to universal access to sanitation. The human rights approach imposes a tripartite obligation on the state as the primary duty-bearer to respect, protect and fulfil the right to sanitation both within its jurisdiction and externally, for instance through developmental assistance to poorer states.

Hence, the state retains the duty to support individuals to access safe, accessible, acceptable and affordable sanitation services, either through direct provision or by creating an enabling environment for third parties to deliver the services. The human rights approach ensures top-down accountability in favour of the rights-holders: this requires clearly defined roles and responsibilities for all stakeholders involved in the delivery of sanitation services.

The human rights approach also imposes a duty on states to ensure that the maximum available resources are allocated to sanitation and that there is no discrimination or retrogression in the process: this enhances the equitable allocation of resources for sanitation.

Finally, there are judicial and non-judicial human rights enforcement mechanisms which empower people living without access to sanitation to demand coverage as a right rather than as a mere act of benevolence from the state.

Conclusion

Although the inclusion of a sanitation goal in the National Health Policy 2016 is laudable and indicative of the recognition of the importance of sanitation for universal access to health in Nigeria, the Policy’s potential is hampered by a limited conceptualisation of sanitation as a component of water quality. The sanitation goal, and the related objectives and policy orientations or initiatives, also fail to reflect the content of the human right to sanitation.

Admittedly, given that the Policy is a health policy, it cannot be expected to address all aspects of sanitation governance. Nonetheless, the need to de-link water and sanitation has already been recognised by scholars as well as United Nations organs such as the General Assembly, which passed a resolution towards the end of 2015 recognising sanitation as an independent right (Feria and Ellis, 2015; Obani and Gupta, 2016).

Moreover, the human rights norm has become a part of global custom, as reflected in the SDGs, for instance. Hence, any modern policy initiative dealing with sanitation can indeed be expected to reflect the core content of the human right to sanitation as a minimum; inasmuch as it fails to do so, the Policy represents a missed opportunity for advancing the human right to sanitation for Nigerians and, in the process, benefiting universal health coverage.

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INTERVIEW

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The United Nations Independent Expert on the Rights of Persons with Albinism with Ms Ikponwosa Ero

Ikponwosa Ero (Nigeria) was designated in June 2015 by the UN Human Rights Council as the first UN Independent Expert on the enjoyment of human rights by persons with albinism. Inspired by her experiences as a person with albinism, Ms. Ero has spent the last seven years fulfilling her mandate.

As international advocacy and legal officer of Under the Same Sun, an NGO with a focus on albinism, she has participated in multiple activities and panels at the UN in Geneva and New York. She has extensive experience in research, policy development and advocacy in the field of albinism. She is the author of numerous papers and articles on the issue, including ones examining the categorisation of persons with albinism in the international human rights system.

Can you briefly tell us about your mandate as the Independent Expert on the enjoyment of human rights by persons with albinism?

My mandate was created nearly three years ago by the Human Rights Council of the United Nations. It was created in response to increasing reports of attacks and other grave human rights violations against persons with albinism. The attacks are linked to witchcraft beliefs and practices, which propagate the absurd and erroneous notion that the body parts of persons with albinism can generate wealth and good luck when used in rituals, potions and amulets. Nearly all reports of attacks have come from sub-Saharan Africa. Globally, there are challenges over and above the attacks, including reports of infanticide, abandonment and discrimination in the areas of socio-economic rights, such as being denied jobs or places at school.

As with all other thematic mandates, I have general duties, such as reporting to the UN Human Rights Council and to the General Assembly, and visiting countries for fact-finding and first-hand assessment of the situation. My main focus in this mandate is to end the attacks against persons with albinism and to tackle their root causes. Consequently, I spend a lot of effort on the region of sub-Saharan Africa, where violations against person with albinism are severe. In so doing, I meticulously search for good practices and also seek out partners to replicate these good practices at the local level and national levels.

I also prioritise research. Since this issue [albinism] has been neglected for centuries and its members have suffered and continue to endure great violations, it is highly important to gather the facts to feed them into ongoing intervention. This means I engage in frequent dialogue with persons with albinism, academic researchers and other stakeholders. I am now working on building an international research collaborative on the issue. The collaborative will look into all relevant legal frameworks, but will also include the difficult questions surrounding harmful practices emerging from belief systems that pervade sub-Saharan Africa.

What is albinism?

The condition of albinism is non-contagious, genetically inherited and affects people regardless of race, ethnicity or gender. It results from a significant deficit in the production of melanin and is characterised by the partial or complete absence of pigment in any or all of the skin, hair and eyes.

Persons with albinism therefore often appear pale in comparison to members of their family and their communities.

Today, it is estimated that in Europe and North America the frequency is 1 in 17,000 to 1 in 20,000 births. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000, with prevalence rates of 1 in 1,000 for selected populations. A higher frequency has been reported in certain parts of the Pacific (1 in 700) and among some indigenous peoples in North and South America (1 in 70 to 1 in 125). While the condition is global, the impact of the condition on human rights, and its perception by others, including its effect on social inclusion, varies from region to region.

There are different types of albinism. The most well-known type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type are subtypes that may reflect varying degrees of melanin deficiency in an individual. Lack of melanin in the eyes results in high sensitivity to bright light and significant visual impairment, with the level of severity varying from one person to another. This visual impairment often cannot be completely corrected. In addition, one of the most serious health implications of albinism is vulnerability to skin cancer, which remains a life-threatening condition for most persons with albinism in certain regions. All violations of civil and political rights relating to albinism reported to date have been linked to its oculocutaneous form, which is also the most visible type of albinism.

Since your appointment as the Independent Expert on the enjoyment of human rights by persons with albinism, what would you consider to be the major challenges facing persons with albinism worldwide, particularly in Africa?

The overarching challenge faced by persons with albinism is long-term neglect of the issue, resulting in the absence of their voice in the public sphere. Also, a significant number of persons with albinism globally are not aware of the laws that protect them and continue to linger in various forms of suffering and neglect. Efforts need to be made to build their capacity (particularly that of civil society leaders and advocates) on the norms and standards of human rights and also on the human rights approach.

The second overarching challenge is a lack of understanding of the condition and consequently a failure to apply a robust legal framework to their experiences.

In the past, there was often a lack of clarity in the application of the disability framework to persons with albinism. Nowadays, with the advent of the Convention on the Rights of Persons with Disabilities (CRPD), which broadened the understanding of disability, persons with albinism are officially a constituency of the larger groups of persons with disabilities. However, in sub-Saharan Africa, this knowledge is not always known widely by state officials, where it's needed the most. Various reports, along with my own experience (even in states that have ratified the CRPD many years ago), confirm that very few national and community-level personnel of the state charged with the implementation of disability rights are aware of the CRPD's implications, including their duties.

In addition to the CRPD, the Convention on Elimination of Racial Discrimination (CERD) also applies to persons with albinism. The Committee governing the CERD has explained that 'racial discrimination' is not only linked to race but to other grounds, such as colour and heritage, and racial discrimination can be found even when these grounds are independent of each other.

National laws on trafficking in body parts – not just in persons – are also highly beneficial to the issue, yet many countries lack this aspect in their trafficking and criminal laws. International and national trafficking laws ought to be applied to address the cross-border aspect of this issue, as cases of body parts and persons moving across borders have been reported. Further, national laws or policies on witchcraft practice also need to be evoked. However, most of these are archaic and need revision in a way that may be helpful to persons with albinism and others who are often victimised by the phenomena.

I have used the plural of 'phenomenon' on purpose, to recognise the plurality of definitions, forms and aspects of 'witchcraft' beliefs and practices. I am also working with experts on the issue to come up with some early-stage understanding of what it means, not only to guide my work but to support the work of countries reviewing their so-called witchcraft laws.

The intersection of these laws provides a thorough understanding of the issues faced by persons with albinism and potential solutions, yet public knowledge of these, and how to implement them effectively, remains lacking.

How have these challenges, particularly the issue of discrimination, affected the enjoyment of socio-economic rights by persons with albinism?

In sub-Saharan Africa, the impact of these overarching challenges is a vicious cycle. Once a child with albinism is born, there is a risk of infanticide and abandonment. Mothers of children with albinism also risk being expelled from their communities on the grounds of alleged infidelity, since the baby has white skin, or on the grounds that the baby is a curse on the family or on the community.

A common consequence is that the child grows up in dire poverty and vulnerability to attacks and other serious human rights violations.

If the children survive this stage, they are unlikely to attain an education due to their visual impairment and the lack of reasonable accommodation for the impairment in the classroom. Moreover, discrimination, bullying and name-calling from students and teachers alike force children not to return to school. The absence of education means persons with albinism often cannot access gainful employment – in particular, employment indoors. Oftentimes, they become farmers, peddlers and petty traders, working outdoors where they expose themselves to the risk of developing skin cancer. Skin cancer is the number-one cause of death in persons with albinism in the region. In some countries, only two per cent reportedly live beyond age 40, with a majority succumbing to this preventable disease.

Furthermore, the absence of work in a secure environment produces endemic fear and impacts the livelihood of persons with albinism, as insecurity often shortens the number of work hours they are able or willing to undertake away from home. Similar impact on the right to work of family members and carers of persons with albinism has also been reported.

Essentially, a significant number of persons with albinism, particularly on the sub-continent, live a Hobbesian life: poor, nasty, brutish and short, with a theme of fear of attack threading through it. It is true that a majority of the attacks, and fears of attack, occur in rural areas, but this should not be a diminishing factor since the lives of people everywhere count – human rights are universal. Moreover, even the people with albinism whom I spoke to in the urban centres in countries with records of attack, do not feel completely safe from attackers seeking their body parts, as there have been a few cases reported from cities.

There are also reported cases of discrimination in the cities. It has been reported that landlords often fear renting their accommodation to persons with albinism, on the basis that 'they would run away overnight to escape attack, leaving their bills unpaid'.

Also, tenancy has been denied to persons with albinism who feared being implicated in attacks, while other landlords feared an invasion of bad luck in their enterprise by having persons with albinism as tenants. In addition, the colouring of persons with albinism in particular is commonly used as a basis to deny employment, on the ground that it would drive clients away or create a perception of contagion, particularly in the food or hospitality industry. This latter issue has been reported in regions outside of Africa.

Do you think African governments are doing enough to address the challenges facing persons with Albinism?

I believe African governments are making good but slow – and in some cases, very slow – progress. However, I am optimistic, because most governments in the region are willing to cooperate with my mandate.

Many citizens have also shown a large amount of resolve to end the attacks. The political and collective will is generally present, as seen in various high-level condemnations of attacks. However, converting these into concrete, effective and sustained results remains the challenge. That said, recorded attacks are reducing in the aggregate, even though they continue to emerge generally. There are also some investments being made by government, civil society activists and myself in terms of filling gaps in law, raising public awareness, and improving self-advocacy among persons with albinism themselves. I use this medium to call on African governments to implement particular measures, as elaborated below.

Are their good practices in addressing discriminatory practices against persons with albinism which you wish to share with us?

Effective good practices involve the adoption of special measures such as national action plans to carry out protection and non-discrimination measures for persons with albinism, while spreading understanding of the condition to demystify it through the use of the applicable science and legal frameworks. Kenya, Malawi, Nigeria and Mozambique all have both de jure and de facto plans and policies addressing issues of persons with albinism. However, implementation remains lacking in many countries. This implementation gap can and has been addressed with the appointment of a champion on albinism into high public office. This singular act is a concrete way of injecting into public affairs the voice of persons with albinism, which has been historically excluded from that sphere of influence. Where government has carried out this affirmative action in a proper way, including through broad consultation with people with albinism themselves and with the goal of sourcing effective advocates on the issue, the result has been significant.

For example, in Kenya, the appointment of a Member of Parliament with albinism was key in ensuring the participation of persons with albinism and channelling their concerns to the decision-makers. His action in championing this cause led to the establishment of an albinism support programme and a desk officer within the National Council for Persons with Disabilities – a state entity established by the Disabilities Act (2003). As a further result of his advocacy, this specific programme has an annual budget of 100 million Kenyan shillings. This is a significant budget, with a large part of the reasonable accommodation measures for persons with albinism being met through the provision of free visual aids, and in terms of health, free sunscreen products..

The visibility of an active Member of Parliament also promoted public education on the condition, highlighted the capacity of those with the condition, and promoted – and continues to promote – social inclusion.

Similarly, in Tanzania, the appointment of a person with albinism as Deputy Minister was widely applauded by all stakeholder and was key to the visibility of the specific needs of persons with albinism. The Member of Parliament also played a championing and coordination role in terms of the initiatives taken by various ministries and civil society.

In Malawi, the participation in public life of persons with albinism is benefiting from the dedication of civil society and government to the international human rights principle of 'nothing about us without us'. This has been increasing the trend of involving organisation of persons with albinism in the development of projects and policies designed to address their security and correlative human right needs.

In May this year, during the 60th Ordinary Session of the African Commission in Niamey, Niger, you shared your thoughts on the Continental Strategy on albinism. Can you tell us more about this and what you hope to achieve with it?

The Regional Action Plan on Albinism in Africa (Regional Action Plan) aims to – through concrete measures – prevent and end attacks against persons with albinism by the year 2021. The timeline seems short when compared to other ambitious Plans. However, in this case, I think it is important to keep it short to remind us of how unacceptable these violations are and the fact that they needed to have ended yesterday.

The Plan is the result of broad consultation with persons with albinism, civil society organisations, African Union mechanisms and United Nations agencies. Moreover, the Plan has been endorsed by the African Commission on Human and People's Rights since the session you refer to in May 2017. The Plan consists of 15 concrete measures of prevention, protection, accountability and equality and non-discrimination.

The implementation strategy lies in the use of the Plan as a broad vision for spurring the adoption of detailed national action plans, each of which adapts the Regional Action Plan to national contexts. The implementation strategy includes the support of international and regional organisations through advocacy work, technical cooperation and direct delivery of programmes and activities, both at the regional level (African Union, cross-border initiatives and sub-regional bodies) and at the national level.

What would you consider to be your major achievements so far since your appointment as Independent Expert?

The regional action plan is certainly a major achievement. It took three consultative forums to achieve the end result. The effort, costs and partner-coordination it took was momentous, but all of this was accomplished in a period of about two years.

Another achievement is the ground-breaking workshop on witchcraft and human rights in Geneva which I will be organising later this year.

Nakulima Saphina is the Senior Program Officer: Right to Education at the Initiative for Social and Economic Rights (ISER). ISER is an independent, not-for-profit human rights organisation responsible for promoting the effective understanding, monitoring, implementation and realisation of economic and social rights in Uganda. Visit <http://www.iser-uganda.org> for more information.

It will be the first time that the issue of witchcraft-related beliefs and practices and the human rights violations it spurs in many cases, will be addressed in depth and systematically at the international level. The phenomena of witchcraft are complex and yet affect thousands of vulnerable people yearly, including, and going beyond, persons with albinism. Consequently, I will work with various experts on the issue to start to create a working understanding, including definitions and measures that might assist governments in tackling impunity around these violations and that mandate-holders such as myself and other experts make on the issue.

A third achievement is the country visits that, to date, have been made to three countries. These include assessment trips to Malawi, Mozambique and Tanzania. The visits have been very fruitful in engaging government on the issue and in discovering more cases of attacks, gathering facts and [identifying] patterns in correlating issues such as the trafficking of body parts of persons with albinism.

What would you like to be remembered for after your tenure as the Independent Expert on the enjoyment of human rights by persons with albinism?

I hope I leave with no attacks happening [anymore], or with the last one that was last heard of having happened long before I left. I also hope that concrete and sustainable steps are put in place to prevent and treat skin cancer in all affected countries, as the condition kills far more persons with albinism than the attacks being reported. I also look forward to ample awareness-raising and self-education for persons with albinism themselves, so that the condition will be less of a novelty and more of a condition of life.

Furthermore, I hope that persons with albinism would be far more empowered to engage with both their governments and the international community in advancing their socio-economic rights and participation in public affairs. I also hope significant inroads would have been made to address and stamp out the root causes of attacks, particularly witchcraft-related beliefs and practices which have spurred the attacks.

Would you want to share any thoughts with African governments on the way forward?

Political will and support are only one side of the coin; implementation is the key for real change in the lives of people. In this regard, there is much more to be done. I would like to reassure African governments that the situation of persons with albinism is one which can be successfully improved over a relatively short period of time.

With estimates of 1 in 1,500 to 1 in 15,000 persons with the condition in the sub-region, quality service to this group is manageable and deliverable at relatively low cost. Their comparatively small number should persuade, not dissuade, an investment of resources. African governments will do well to see the issue for what it is: a litmus test of their commitment to all human rights for those in vulnerable situations. *Some excerpts of this article have been taken from her report to the UN General Assembly (2017, to be*

published), and from her article in Women's Rights in Africa, 'Persons with albinism, in particular women'. For more, read: >http://www.ohchr.org/Documents/Issues/Women/WRGS/WomensRightsinAfrica_singlepages.pdf.

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3 Events

Workshop unpacks issues around women's involuntary sterilisation in South Africa

In commemoration of Women's Month, the Socio-Economic Rights Project (SERP) convened a one-day Stakeholders Engagement Workshop on 7 August 2017 on involuntary sterilisation of women in South Africa as gender-based violence.

Although South Africa has developed policies that address the practice of involuntary sterilisation, what is missing is a framework that recognises and links it to vulnerability and gender-based violence as well as to the proper enforcement of policies.

The workshop brought together a cross-section of stakeholders to address the issue of involuntary sterilisation of women holistically as a human rights violation. Participants included representatives of relevant government departments, the medical profession, public health practitioners, Chapter 9 institutions, local community leaders, and members of academia and civil society organisations active in women's rights.

Adopting an interdisciplinary approach, the workshop aimed to broaden understanding of, and highlight issues around, involuntary sterilisation, create awareness, and galvanise the process of advocacy and policy change.

One of the key points made at the workshop was that there is a crucial need for human rights training for health practitioners and community members

on the sexual and reproductive health and rights of women; likewise, there is a need to redefine 'consent' in the context of procedures such as sterilisation and view it as a 'process rather than an event'.

Participants also expressed strong views about revisiting the prescription period for matters of involuntary sterilisation, given the attendant psychological effects this has on women. It was the general consensus that involuntary sterilisation of women and its continued practice is indicative of the unequal power balance in society, an imbalance that perpetuates the cycle of violation of rights.

Roundtable discussion on 'just cities'

On 13 September 2017, the Socio-Economic Rights Project (SERP) at the Dullah Omar Institute at the University of the Western Cape organised a roundtable focusing on challenges to South African cities' being 'just cities' – cities that use their constitutional and economic clout to enhance the well-being of all city-dwellers in an inclusive and developmental manner.

One of the most visible nature of South Africa's system of multi-level government is the increasing role of metropolitan and secondary cities. The South African city is a microcosm where high economic potential, rapid immigration, urban poverty, environmental degradation and diversity are combined in a local state with constitutionally protected powers. Driven by the need to address urban problems and afford opportunities, cities are asserting their constitutional and economic power and being forced to be at the forefront of devising new strategies to deal with informality.

South Africa's cities thus have significant potential to enable poor and working-class people to advance economically and socially.

At the same time, the conduct of cities in addressing informality (by, among other things, upgrading informal settlements and evacuating dangerous buildings) is coming under the legal spotlight owing to a spate of court judgments relating to the right of access to housing and other socio-economic rights.

The roundtable discussion, facilitated by Gladys Mirugi-Mukundi of the Dullah Omar Institute, had three expert panelists: Dr Margot Strauss (SERAJ, Faculty of Law, Stellenbosch University), Prof. Jaap De Visser (Dullah Omar Institute), and Dr Rike Sitas (African Centre for Cities, University of Cape Town).

In a presentation entitled 'Understanding housing, as if space and justice matter', Dr Strauss observed that despite improvements in the state-subsidised housing programme, human settlements in South Africa continue to be developed without the necessary preplanning requirements for township establishment and the requisite infrastructure and services for making them functional and sustainable. In the lived experience of citizens, human settlements remain fragmented, with poor households being situated – 'dislocated' – in outlying areas. Although the combination of spatial planning, human settlements and housing is intended to redress past imbalances and urban segregation, there is a need, according to Dr Strauss, for alternative thinking to complement the emphasis on law in general and planning laws in particular.

Prof. De Visser's presentation, 'Just Cities and SPLUMA: Business as usual?', focused on the Spatial Planning and Land Use Management Act (SPLUMA), Act 16 of 2013, which provides a framework for spatial planning and land use management in South Africa. In accordance with this framework, all spheres of government must prepare spatial development frameworks. Consistent with the requirements of SPLUMA, both national and provincial Spatial Development Frameworks for Human Settlements must be developed to ensure integration of services, infrastructure and economic development.

Dr Sitas's presentation, entitled 'Realising Just Cities', stemmed from a joint project in which she is involved. She suggested that in order to realise just cities, academics, researchers, city officials, urban planners, legal practitioners and community members need to comprise a 'talking lab', one in which the different stakeholders and participants adopt a multi-dimensional approach and complement in each other in working towards 'a vision of a just city'.

The roundtable discussion provided an opportunity for academics, community-based organisations, NGOs, policy-makers and stakeholders to deliberate on the challenges of realising 'just cities.' The presentations stimulated much discussion on how cities can overcome problems of spatial justice; the need for greater understanding of SPLUMA; the role of the courts and jurisprudence in advancing spatial justice; and practical examples of 'just cities' around the world.



Updates

CEDAW Committee adopts General Recommendation 35 on Violence against Women

Twenty-five years after its adoption of General Recommendation 19 on violence against women, the CEDAW Committee on 14 July 2017, adopted General Recommendation No. 35 on gender-based violence against women. This serves as an update of General Recommendation No. 19. The new General Recommendation among others establishes new standards on various aspects of violence against women, including its implication for sexual and reproductive health and rights, the need to change social norms and stereotypes that support violence, explicitly defining different levels of liability of the State for acts and omissions committed by its agents or those acting under its authority and for failure to act with due diligence with a view to prevent violence against women. It urges states to take concrete measures to repeal laws and policies that condone violence against women. The Committee notes that violence against women may interfere with the enjoyment of other rights such as life, dignity, health, liberty and security of the person, equality and equal

protection within the family and freedom from torture, cruel, inhumane or degrading treatment. More importantly, in acknowledging the intersectionality of violence against women, the Committee notes that ‘violence may affect some women to different degrees, or in different ways, meaning that appropriate legal and policy responses are needed’.

The General Recommendation is available here http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CEDAW/C/GC/35&Lang=en

Report of the UN Special Rapporteur on the Right to Safe Drinking Water and Sanitation on service regulation

During the 36th Session of the Human Rights Council in September 2017, the UN Special Rapporteur on the right to safe drinking water and sanitation presented a report focussing on service regulation and the human rights to water and sanitation. The report notes that articles 2 and 11 of the International Covenant on Economic, Social and Cultural Rights obligate States to take deliberate, concrete and targeted steps to establish a regulatory framework for water and sanitation service consistent with State’s obligations to respect, protect and fulfil these human rights. The report notes that while adopting regulatory frameworks on water and sanitation, states must safeguard provision of services to homeless people, dispersed communities, and to victims of situations of armed conflict, emergencies, natural disasters or climate change effects. It further notes that states must ensure that regulation does not in any way interfere with the enjoyment of affordable services to vulnerable groups. It specifically notes that all service providers-state and non-state actors- must comply with the state regulatory framework. In particular, non-state providers of services do have human rights responsibilities to observe.

The reports of the Special Rapporteur are available here <http://www.ohchr.org/EN/Issues/WaterAndSanitation/SRWater/Pages/Annual-Reports.aspx>

The ESR Review is a quarterly publication that aims to inform and educate politicians, policymakers, NGOs, the academic community and legal practitioners about key developments relating to socio-economic rights at national and international levels. It also seeks to stimulate creative thinking on how to advance these rights as a tool for poverty alleviation in South Africa and abroad.

Contributions:

should reflect contemporary debate or spark new debate;
 should be opinion pieces or serve an advocacy function, rather than simply stating legal principles or being descriptive in nature;
 should not be on a topic already published in the ESR Review, unless they take the debate forward;
 should not be a marketing exercise for a particular project or programme; and should be written in a simple, clear style that avoids technical language and legal jargon where possible, taking into account that the ESR Review is read by both legal practitioners and grassroots human rights organisations.

Send contributions in electronic format (MSWord) to serp@uwc.ac.za. Provide your full name and present position. Titles and qualifications are not necessary.

If the article has already been published elsewhere, give full details, including whether it has been shortened, updated or substantially changed for the ESR Review and whether the required authorisations have been granted.

Length

Contributions should be no longer than 3 000 words, except contributions for the Events section (1 500 words) and the Publications (Book Review) section (1 000 words).

Previous issues of the ESR Review are available online: <http://dullahomarinstitute.org.za/socio-economic-rights/esr-review>



Call for contributions to the ESR Review

The Socio-Economic Rights Project of the Community Law Centre at the University of the Western Cape welcomes contributions to be published in the ESR Review.

