



THE TENSIONS BETWEEN CULTURE AND HUMAN RIGHTS: Emancipatory Social Work and Afrocentricity in a Global World

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Misrecognition of the Rights of People with Epilepsy in Zimbabwe: A Social Justice Perspective

Jacob Rugare Mugumbate and Mel Gray

Epilepsy affects 4 to 14 people per 1,000, that is, an estimated 50 million people worldwide, making it the most common global neurological condition (Shorvon, 2009; WHO, 2016). It is more prevalent in the Global South, where 80 percent of people with epilepsy reside, due to “poorer perinatal care and standards of nutrition and public hygiene, and the greater risk of brain injury, cerebral infection, or other acquired cerebral conditions” (Shorvon, 2009, p. 3). In Africa alone, epilepsy directly affects about 10 million people (WHO, 2015). Indigenous cultural and religious misunderstanding affects the management of this neurological condition in many parts of the world, especially in Africa. This has led to misrecognition of the rights of people living with epilepsy, which leaves them socially isolated and makes it difficult for them to develop social networks and to access treatment, education and training, and employment. This chapter explores the misrecognition and misrepresentation of people with epilepsy, and associated injustices relating to dominant indigenous cultural and religious perspectives on epilepsy in Africa and consequent human rights omissions found in a study of persons with epilepsy in Harare, Zimbabwe. It provides an overview of perspectives on epilepsy in Africa and the injustices stemming from the continued exclusion of people with epilepsy in Zimbabwe. It suggests that Nancy Fraser’s (2000, 2001, 2008,

2010) theory of social justice offers a framework for understanding the injustices ensuing from the misrecognition of people with epilepsy and ends by suggesting an integrated rights-based model for epilepsy management in Zimbabwe and other African countries.

Dominant Historical Indigenous Cultural and Religious Perspectives

In Africa, as in other parts of the world, non-medical interpretations of epilepsy abound. Indigenous cultural and religious perspectives view epilepsy as a contagious spiritual condition caused by supernatural forces treatable through cultural and/or religious practices. These are sometimes termed complementary or alternative therapies (CAMs), and traditional healers use them instead of, or in combination with, conventional biomedical interventions (Baker, 2002, Ferguson, 2012; Green, 2000; Mushi et al., 2011). Though understandings of epilepsy vary from society to society in Africa, historically they are rooted in indigenous, cultural, and Christian and Islamic religious beliefs.

Indigenous cultural perspectives

Traditional healers advocate various methods of healing given their belief in epilepsy's supernatural origins. In Zimbabwe, for example, a popular indigenous healing ritual involves locating the witch responsible for supernatural interference and destroying her medicines or goblins to render her powerless (Chavunduka, 1986). Ceremonial offerings as diverse as alcohol and animals are made to appease an angry god or ancestors, while the person with epilepsy, or family elders, pray for healing, deliverance, and forgiveness (Epilepsy Support Foundation [ESF], 1992; Mutanana & Mutara, 2015). People swallow, inhale, or insert herbs into the bloodstream through small cuts on the skin (ESF, 1992). Prescriptions include drinking, or bathing in, animal fat, blood, or urine or rubbing it on the skin or the wearing of red cloths and beads, or refraining from certain foods (Chavunduka, 1986). Healers often run shrines where people with epilepsy receive treatment. Researchers found indigenous healing methods similar to those in Zimbabwe in Uganda, Tanzania, Malawi, Morocco, South Africa, and Zambia (Baskind & Birbeck, 2005a; Duggan, 2013; Ferguson,

2012; Keikelame & Swartz, 2015; Mushi et al., 2011; Watts, 1989; Winkler et al., 2009). In most of these countries, people link epilepsy to witchcraft curable only by traditional healers. In Malawi and South Africa, traditional healers claim to treat the spiritual cause of epilepsy but agree that its physical manifestations require medical treatment (Keikelame & Swartz, 2015; Watts, 1989). These culturally embedded explanations often misrecognize epilepsy. This leads to violations of people's rights to medical treatment, education, employment, marriage, and inheritance. Misconceptions about epilepsy reinforce the stigma and marginalization faced by people with epilepsy and their families (Baskind & Birbeck, 2005a).

Religious perspectives

Some African Christians believe that Satan, demons, and evil spirits cause epilepsy. In the Bible, Jesus healed a demon-possessed boy: "Lord, have mercy on my son. . . . He has seizures and is suffering greatly. He often falls into the fire or into the water. I brought him to your disciples, but they could not heal him" (Matthew 17:14–16, New International Version). Another example from the Bible says, "She had suffered a great deal under the care of many doctors and had spent all she had, yet instead of getting better she grew worse" (Mark 5:26, New International Version). These verses strengthen religious interpretations of epilepsy, although, in this case, Jesus healed the woman of chronic bleeding, which she had endured for 12 years. The Bible says Jesus healed her when she touched his robe and he said, "Daughter, your faith has healed you. Go in peace and be freed from your suffering" (Mark, 5:34, New International Version). Most churches in Africa advise adherents to have faith in God, read the Bible, fast, pray, and seek help from prophets, who use anointing oils, water, stones, and touch for healing. Some churches entreat patients to wear bracelets with Bible verses or a waistcloth.

Adherents of the Islamic religion believe illness comes from Allah or God, as a test of faith in Allah, or an atonement for past sins (Mughees, 2006). They believe Allah created, and is responsible for healing, every disease: "And when I am ill, it is He who cures me" (Quran, 26:80). Sickness is a wake-up call for enhanced spiritual connection with God through prayer, charity, meditation, forgiveness, or remembrance of Allah and reading the Quran (Lawrence & Rozmus, 2001). In Morocco, for example, people

view epilepsy as a religious, supernatural, and cultural condition caused by evil spirits or demons called *jinn* (Ferguson, 2012). A *fquih* or an imam, a religious scholar well-versed in the Quran, uses his supernatural powers to speak with, and expel, the *jinn*, while touching the patient. If this fails, the *fquih* recites passages from the Quran or treats the “possessed person” with smoke and scents. Sick people often wear charms and amulets with Quran verses on them to stave off evil. If none of these rituals work, this means the *jinn* has married the patient, parented children, and is unwilling to leave. To prevent evil possession, people must have faith in Allah and the Prophet Mohamed, pray and perform daily rituals and ablutions, and avoid haunted places, such as dark spaces and abandoned buildings (Ferguson, 2012).

These indigenous cultural and religious models persist in the absence of evidence of their effectiveness in treating seizures and managing epilepsy, and many argue we should not dismiss them without further evaluation (Baskind & Birbeck, 2005a; Green, 2000; Watts, 1989, 1992). There are some similarities between traditional and modern medical approaches. Both involve assembling a thorough historical background to reach a diagnosis, agree on epilepsy’s genetic aetiology, and suggest dietary practices, such as abstention from alcohol (Baskind & Birbeck, 2005b; Magazi, 2017). One might equate the psychosocial support ensuing from cultural and religious consultations, rituals, and ceremonies to the benefits of counselling and group therapy in Western psychology. Furthermore, indigenous methods are often more socio-culturally acceptable and accessible than biomedical treatment

Contemporary Perspectives on Epilepsy

Biomedical perspective

From a biomedical perspective, epilepsy is a chronic, non-communicable neurological condition characterized by recurrent seizures and long-term social stigma (Baskind & Birbeck, 2005a; Shorvon, 2009; WHO, 2016). Medically, seizures emanate from neurons in the brain, the nerve cells responsible for communication between the brain and the body, through the transmission of electrical impulses. A disturbance in this transmission

process may result in an excessive discharge of “messages,” with body parts failing to respond. This may lead to lapses in attention, loss of sensation, jerking movements, falling, or muscle stiffening. Such disturbances are largely the result of brain damage, either before or after birth (WHO, 2005, 2016). There are numerous causes of brain damage, including a lack of oxygen to the brain, head trauma at birth, or accidents, drug or alcohol abuse, brain tumours, genetic syndromes, and infections, such as meningitis. Most of these causes are preventable or treatable through lifelong daily doses of anti-epileptic medication or, in some cases, brain surgery. The discovery of potassium bromide in 1857 strengthened the biomedical model (Scott, 1992) and positioned people with epilepsy as patients in need of health care. Supported by scientific research, medical treatment became the most effective method of seizure control in Africa, as elsewhere. Other treatment approaches include a ketogenic diet and vagus nerve and deep-brain or trigeminal nerve stimulation (International Bureau for Epilepsy [IBE], 2014).

Non-Western treatments for epilepsy, often termed complementary, alternative, or non-conventional, include religious and cultural practices, herbal remedies, homeopathy, aromatherapy, acupuncture, and Chinese medicine. Uncontrolled epilepsy temporarily or permanently limits daily activities, such as speech, mobility, memory, sensation, and social interaction (Birbeck & Kalichi, 2003). Control of epileptic seizures has improved as advances in medicine have significantly increased the number of people living seizure-free, productive lives. Despite affordable medical treatment for epilepsy, clinicians do not properly diagnose or treat most people with the condition in resource-poor settings (Baskind & Birbeck, 2005a; Shorvon, 2009). Poverty creates a medical treatment gap ranging from 25 to 100 percent in some communities (Newton & Garcia, 2012).

Biopsychosocial perspective

The biopsychosocial perspective views epilepsy as a biological (physical), psychological, and social issue requiring multipronged interventions (Baker, 2002; de Boer, 2010; Dekker, 2002; Elger & Schmidt, 2008; Mugumbate et al., 2017). The first pillar is physical, as discussed under the biomedical perspective. The second is psychological and includes depression, anxiety, stigma, and low self-esteem (Baker, 2002; Dekker, 2002). The

important addition of the tripartite biopsychosocial was the recognition of its social impacts and the need for social policy, social services, social care, and social support for people with epilepsy. Most importantly, it recognizes the structural factors that result in stigma and discrimination, and the marginalization and exclusion of people with epilepsy (Dekker, 2002; Mugumbate et al., 2017). It seeks to address the socio-cultural, economic, and political barriers to their participation in society, including unfriendly workplace policies and practices and ignorance about epilepsy. It highlights the importance of public education and awareness to reduce the stigma, which is sometimes more difficult to overcome than the seizures (Dekker, 2002; Elger & Schmidt, 2008; Mugumbate et al., 2017). The International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) have promoted the biopsychosocial model and, with the WHO, embarked on a Global Campaign Against Epilepsy. The campaign sought to advance the rights of people with epilepsy contained in the WHO Resolution by urging member states to strengthen access to health and social care for people with epilepsy (WHO, 2015).

Disability perspective

There is debate on whether epilepsy is a disability (Calvert, 2011; Epilepsy South Africa [ESA], 2014) because it is a medically treatable condition. Once treated, it leads to normal social functioning for most people with epilepsy. However, epilepsy is a disabling condition for many people in Africa due to prevailing socio-cultural attitudes that lead to social stigma, discrimination, and exclusion and a lack of appropriate social and health care resources (Baker, 2002). Without appropriate biomedical treatment, it leads to impaired cognitive functioning, intellectual capacity, and physical ability and has psychological impacts, such as depression and anxiety (WHO, 2016). The WHO's (2001) definition of epilepsy aligns with the social model of disability that promotes holistic biopsychosocial intervention for people with epilepsy. Calvert (2011) pointed to the complex interrelationship between epilepsy and disability, while the ESA (2014) argued that epilepsy fits the definition of disability in the Employment Equity Act (Government of South Africa, 1998) and the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) in terms of impairment and barriers to equal participation. The ESF in

Zimbabwe is registered as a disability organization, and some people with epilepsy, disabled by the condition, qualify for (though few receive) government disability payments. Most epilepsy associations in Africa form part of the region's disability movement, even though many people with epilepsy are able bodied, since seizure control enables them to live full and satisfying lives.

Economic perspective

An economic perspective evaluates epilepsy in terms of its socio-economic impacts, such as low economic and employment participation and high health care and social care costs. It suggests interventions for economic empowerment such as those offered by Epilepsy South Africa (ESA, 2014). They include sheltered workshops in Cape Town employing people with epilepsy in a factory supplying furniture to local and foreign markets and another producing mats and baskets. ESA (2014) administers a program named the Epilepsy Disability Employment Support Services (eDESS) to provide employment preparation, workplace adjustment, legal compliance, skills development, and mentoring. The Employment Equity Act (Government of South Africa, 1998) promotes affirmative action, education and vocational training, and sensitization of employers to foster positive attitudes toward people with epilepsy. The IBE (2014) supports self-help projects in Cameroon, Kenya, Uganda, Zambia, and Zimbabwe.

Human rights perspective

With the WHO Resolution and Global Campaign Against Epilepsy, the focus shifted to a rights-based social justice approach. This approach focuses on legal entitlements and guarantees and calls for international and national government action to address economic, socio-cultural, and political inequities and reduce disadvantages for people with epilepsy. Like the social model of disability, it extends individualistic medical and biopsychosocial interventions to address structural and political barriers to justice and identify injustices resulting from misrecognition of the rights of people with epilepsy. The WHO Resolution best reflects the human rights perspective that informed the Zimbabwean study described below.

Misrecognition of the Rights of People with Epilepsy: Findings from a Zimbabwean Study

Background to the study

A qualitative study was conducted using semi-structured, in-depth interviews with 16 unemployed and 14 employed people with epilepsy (n=30), who were members of the Epilepsy Support Foundation (ESF) in Harare, Zimbabwe's capital. The study sought to identify social injustices arising from misrecognition of the rights of participants through lack of access to educational and vocational support, health services, public social welfare and disability support, employment services, and recourse to justice. The participants comprised 13 females and 17 males with a mean age of 33 years. To deepen understanding of the interview findings, the perspectives of ESF service providers (n=7) were sought through a focus group discussion. They included two nurses, three social service workers, and two advocacy workers. The two datasets were analyzed separately using NVivo, a computer-assisted, qualitative data-analysis package. The findings of this study include: (1) lack of educational and vocational support services; (2) lack of medical health services; (3) lack of public social welfare and disability services; (4) lack of employment opportunities; and (5) lack of recourse to justice in the workplace.

Lack of educational and vocational support services

Consistent with the literature, participants reported a lack of educational and vocational services (Elger & Schmidt, 2008; Mushi et al., 2011) even though the Education Act (Government of Zimbabwe, 2001) mandated the government to provide accessible subsidized education for all, including free education for people with disabilities, such as epilepsy. However, due mainly to misinformation and stigma, the participants experienced barriers to education, in an education system once considered one of the best in Africa (UN Development Programme [UNDP], 2013). Participants with childhood-onset epilepsy reported limited access to primary and secondary school education. Some had attended sporadically, while others had dropped out of school. Some teachers had not known about medical treatment or had not supported it, encouraging students with epilepsy

to seek traditional healing. Services to support vocational training were equally lacking. None of the participants had benefited from the government-run vocational training and human-resource development schemes, apprenticeships, cadetships, and scholarships. Service providers were critical of government rehabilitation services, such as Ruwa Rehabilitation Centre near Harare, which offered medical rehabilitation and job-skills training, as its capacity was low, it was highly selective, and it favoured people with physical disabilities.

Lack of medical health services

Health services were of poor quality and expensive and beyond reach for most study participants. Consistent with findings from studies in Malawi and many other African countries, people with epilepsy in Zimbabwe delayed treatment by several years (Baskind & Birbeck, 2005a; Watts, 1989, 1992; WHO, 2016). Vital medicines and medical services were often not available and, when they were, were expensive. The Health Services Act (Government of Zimbabwe, 2004) promised the availability of health services, yet most people with epilepsy in this study could not afford hospital bills and essential medicines. Though public health services were available in urban areas, their quality was erratic. Hospitals were overcrowded and under-resourced, while the community health workforce lacked the capacity to complement hospital-based treatment or to educate communities about epilepsy and the ease with which they could treat it if they properly understood it as a neurological condition. Another factor that compromised health services related to health personnel, notably the fact that there was no neurologist available in Zimbabwe at the time of the research. Service providers reported that nurses, not trained to manage epilepsy, had most often attended to them. Long waiting lists for doctors to diagnose and treat them increased delays to medical treatment. Previous studies in Zimbabwe and other African countries have reported issues of poor health services and inadequately trained nurses (Baskind & Birbeck, 2005a; Duggan, 2013; Mushi et al., 2011).

Lack of public social welfare and disability services

There were no welfare and disability services, and the families of most participants, who were poor, had trouble accessing public services. They

could not meet their basic needs for health, education, and food without government assistance, let alone gain employment skills or startup capital for informal enterprises, as confirmed by service providers in this study. None of the participants was receiving government social assistance even though the Social Welfare Assistance Act (Government of Zimbabwe, 1988) and the Disabled Persons Act (Government of Zimbabwe, 1992) provided for minimal monthly means-tested disability grants of US\$20. Since these depended on the type and severity of the disability, people with epilepsy, who did not have recognizable impairments, were often excluded.

Lack of employment opportunities

There were no social interventions or dedicated government disability employment services for most participants in this study even though Zimbabwe's National Employment Services department was supposed to enhance people's employment prospects. The ESF and other non-government organizations did not offer dedicated employment services. Studies have shown that economic problems were paramount for people with epilepsy (Mugumbate & Nyanguru, 2013), yet none of the participants received income support services.

Lack of recourse to justice in the workplace

Participants were unable to challenge unfair dismissals related to seizures in the workplace or other discriminatory employment practices in court. Existing legal channels, such as they were, were expensive, as lawyers who could help them navigate the complex legal system charged exorbitant fees. While the Labour Court of Zimbabwe was a sound institution, without legal assistance they could not withstand the counter-challenge of their employers. Further, it took a long time before judges heard cases or delivered judgments. There was little chance of success in a policy environment characterized by negative social attitudes toward people with epilepsy. Although the Disabled Persons Act (Government of Zimbabwe, 1992) had anti-discrimination clauses, no one had brought a case to court. Thus, those facing discrimination suffered in silence, as did the participants in this study who effectively had no recourse to justice.

Nancy Fraser's Theory of Social Justice

Feminist political philosopher and critical theorist Nancy Fraser offers a theoretical explanation for why injustices such as the misrecognition of rights found in the Zimbabwean study described above, and other African studies, persists. She proposes a three-dimensional theory of social justice encompassing the economic, cultural/legal, and political domains (Fraser et al., 2004). She views social injustices as emanating from structural inequalities arising from maldistribution, misrecognition, and misrepresentation in the economic, cultural/legal, and political domains respectively. Her framework is particularly pertinent to the multifaceted issues facing people with disabilities in Zimbabwe, who endure economic disadvantage and social stigma, and lack a political voice. Even though her work does not address disability directly, it analyzes social harms generally (Danermark & Coniavitis, 2004). In her early theorizing, Fraser was interested in the intersection between “economic inequalities and culture and discourse” (Fraser et al., 2004, p. 375). She initially drew an analytic distinction between two conceptions of injustice, which she saw as closely interwoven in practice: “socioeconomic injustice . . . rooted in the political-economic structure of society [and] cultural or symbolic [injustice which is] . . . rooted in social patterns of representation, interpretation, and communication” (Fraser, 1995, p. 70). She saw all forms of injustice as “rooted in processes and practices that systematically disadvantage some groups of people vis-à-vis others” (Fraser, 1995, p. 71). Such groups included women; racial, ethnic, religious, and sexual minorities; some nationalities; unemployed and poor people; and people with disabilities. Economic and cultural forms of injustice were pervasive in society and in need of remedying (Fraser, 1995). As Fraser explained in an interview with Dahl, Stoltz, and Willig in 2004, in the 1980s, she found herself drawing on Karl Marx and Max Weber. She argued for “an account of modern society as comprising two analytically distinct orders of stratification, an economic order of distributive relations that generated inequalities of class and a cultural order of recognition relations that generated inequalities of status” (Fraser et al., 2004, p. 377).

Later, she argued for a third form of injustice, political subordination (Fraser, 2008, 2010). Neither redistribution nor recognition was adequate

for this kind of injustice, resulting in a third remedy, representation, or democratic participation. Fraser's final argument was that these three remedies could potentially address injustice if disadvantaged people could participate in society as peers. Hence, parity of participation was pivotal to Fraser's theory of social justice. She argued that, to remedy injustice, marginalized groups had to participate as peers economically, culturally and legally, and politically. Hence, parity of participation was a core dimension of Fraser's theory that cut across all three forms of injustice and their remedies, all of which were central to the claims of people with disability.

Fraser (2001) argued that social justice did not require group identity recognition but rather recognition of the status of individuals making up a group or of the group itself relative to other groups. Taken in the context of disability, this meant recognizing not only individuals as unique actors who were being denied the opportunity to participate as equals in society, but also groups of people being stigmatized because of their differences. Fraser (2001) argued for "parity of participation" to allow "all (adult) members of society to interact with one another as peers" (p. 6). This meant participation in economic (redistribution), cultural and legal (recognition), and political (representation) forums. Redistribution involved dealing with welfare dependence, inequality, deprivation, exploitation, and other factors that denied people opportunities to interact with their equals as peers (Fraser, 2008, 2010). Parity of participation required acceptance of differences, respect for diverse identities, and equal treatment. Justice required fair interaction in society, so all could participate as peers to dismantle "patterns of advantage and disadvantage that systematically prevent some people from participating on terms of parity" (Fraser et al., 2004, p. 378). Fraser argued that injustice pertained "by definition to social institutions and social structures" (Fraser et al., 2004, p. 378) and the barriers that prevented marginalized individuals and groups from participating as peers (Danermark & Coniavitis, 2004). Consistent with Fraser's theory of social justice, this chapter argues that the barriers faced by people with epilepsy result in injustices, most notably misrecognition due to pervasive indigenous and cultural beliefs about epilepsy and the resultant social stigma and reduced access to resources and opportunities attendant upon this. We now examine the potential of a rights-based approach to foster recognition for people with epilepsy.

Rights-Based Approach to Foster Recognition for People with Epilepsy

A rights-based approach to foster recognition for people with epilepsy would include the following measures: (1) public education and awareness programs; (2) research on indigenous cultural and religious approaches; (3) an improved policy environment; (4) adequate resourcing and funding; and (5) enhanced representation.

Public education and awareness programs

Persistent indigenous and cultural misunderstandings of epilepsy in Africa lead to unfounded misrecognition. Public education about epilepsy and attendant outmoded cultural practices would overcome the ignorance, stigma, and discrimination arising from negative social attitudes toward people with epilepsy. As described by participants in this study, we could learn from the successful HIV and AIDS campaign model that enjoyed widespread political support and attracted adequate funding to curtail AIDS-related stigma. The behaviour change campaign for HIV was aligned with effective free treatments and community-based health offered by village health workers. An epilepsy awareness campaign should target traditional healers, schools, communities, and service providers, including government agencies.

Research on indigenous cultural and religious approaches

Traditional methods remain popular and compete with medical treatment in Africa. Recognition of traditional healing acknowledges cultural diversity though it overlooks questions of efficacy and the lack of evidence to justify its continued use. This violates rights to effective medical treatment and reduces opportunities for achieving a better quality of life for people with epilepsy. Without common ground, the medical treatment gap in Africa would be difficult to close. A research program on the effectiveness of traditional treatments might assist in highlighting the complementarity between traditional and medical interventions. This type of research might also highlight potential harm of both traditional and Western medicines and develop strategies to address them.

Improved policy environment

Zimbabwe needs a comprehensive and inclusive National Epilepsy Policy to give effect to the WHO Resolution and provide for coordinated government and non-government service provision, including accessible and affordable medical treatment; social, educational, and employment support; and improved case management. A special board and epilepsy fund would support the implementation of the epilepsy policy in schools and training institutions, providing inclusive guidelines for children and adults with epilepsy to achieve an equitable free education. It should provide standards to regulate traditional cultural and religious healing. It should include employer-friendly work policies for people with epilepsy and access to legal support in cases of unfair dismissals or exclusionary employment practices.

Adequate resourcing and funding

The National Epilepsy Policy – through the special board and epilepsy fund – should ensure adequate resources, including free first- and second-line medical treatment and supportive health services with well-stocked primary health care clinics to ensure early seizure control and ongoing seizure management following the HIV and AIDS model. It should ensure the availability and affordability of third-line specialist services and medications, where appropriate. A dedicated training budget should ensure training for schoolteachers, primary health care nurses, and employers to ensure an inclusive educational, health care, and work environment for people with epilepsy. Parent education programs should ensure that parents, too, receive education and support, along with assistance with school and medical costs. Finally, community education and awareness programs would ensure responsive, inclusive, and informed community members.

Enhanced representation

Disabled People's Organizations (DPOs) need to enhance representation for, and build their capacity to ensure, the rights of people with epilepsy, especially since, in Zimbabwe, the government has failed to expand public services or support non-government services for people with epilepsy. They should advocate for increased financial and technical support for

DPOs, including grants for staff salaries and research, and air time on public broadcasting media, including radio, television, and newspapers.

Conclusion and Recommendations

The misrecognition of people with epilepsy arises from structural factors that lead to social injustice and the denial of opportunities to participate as peers in society. These structural barriers arise from avoidable misinformation and stigma. There is an urgent need for economic and socio-cultural measures, including reduction of poverty, and public education and awareness to ensure recognition of people with epilepsy. This chapter drew on Nancy Fraser's (2000, 2001, 2008, 2010) theory of social justice, which essentially accords with the recommendations based on Afrocentricity and *Ubuntu* discussed in the Conclusion chapter, to inform a National Epilepsy Policy and an integrated epilepsy-management model aimed at the recognition of, and representation for, people with epilepsy, and to achieve parity of participation for them.

Prior epilepsy-management models, such as Watts (1989) and the Global Campaign Against Epilepsy (2012), focused on medical treatment and overlooked social and economic impacts for people with epilepsy and their families. The resultant individualistic approach neglected systemic and structural factors that disadvantaged people with epilepsy, such as poverty, lack of representation, culture, and barriers to education and employment. An integrated model of epilepsy management would focus on the diverse economic, cultural/legal, and political factors that affect the well-being of people with epilepsy and include economic redistribution, cultural and legal recognition, and political representation respectively as follows:

1. Economic redistribution
 - a. Adequate supply of free anti-epileptic drugs and epilepsy-management services.
 - b. Health education and promotion through accurate information about the nature of epilepsy and the availability of effective medical treatment.

- c. Policies to ensure income transfers, social welfare support, and adequate funding of essential services.
 - d. Accessible education and training and employment services and opportunities.
2. Cultural/legal recognition
- a. Training for educators, employers, service providers, parents, and community members to provide accurate information about epilepsy and its treatment and recognition of disabling stigma that disadvantages people with epilepsy and their families.
 - b. Standards for, and regulation of, traditional treatment methods.
 - c. Targeted national epilepsy legislation and management plans to implement the WHO Resolution.
3. Political representation
- a. Support for DPOs to give voice to people with epilepsy to break down structural barriers to education and employment and ensure adequate health care and service provision.
 - b. Access to the legal system to challenge injustices against people with epilepsy in schools, workplaces, and other social institutions.

An integrated model would support health and social service providers in ensuring recognition of the rights of people with epilepsy. Within Fraser's model, these injustices result from the maldistribution of resources and opportunities, misrecognition through stigma and discrimination, and misrepresentation due to their lack of voice in ensuring rights-based justice. Legal measures are essential to ensure the fulfillment of the rights of people with epilepsy to education, employment, and recourse to justice (Fraser, 2000). Misrecognition subjects people with epilepsy to stigma and prevents them from participating as peers in society. An integrated

epilepsy-management model would focus on removing the barriers that prevent parity of participation for people with epilepsy (Fraser, 2008).

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