# Disability, employment, and social justice

## Employment experiences of people with epilepsy in Harare, Zimbabwe

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# Statement of originality

The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

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Jacob Mugumbate

July 2017

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# Publications and conference presentations from this research

**Book chapters**

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**Journal articles**

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# Contents

# Tables, Figures, and Vignettes

**Tables**

**Figures**

**Vignettes**

# Abbreviations

| | |
|---|---|
| ADB | African Development Bank |
| AIDS | Acquired Immunodeficiency Syndrome |
| AJOL | African Journals Online |
| ARI | African Rehabilitation Institute |
| ATR | African Traditional Religion |
| AU | African Union |
| CBR | Community Based Rehabilitation |
| CGPEPD | Code of Good Practice on the Employment of People with Disabilities |
| CPRD | Convention on the Rights of Persons with Disabilities |
| CT scan | Computed Tomography scan |
| DPF | Disabled Persons Fund |
| DPM | Disabled People's Movement |
| DPO | Disabled Persons Organisations |
| eDESS | Epilepsy Disability Employment Support Services |
| EDLIZ | Essential Drugs List for Zimbabwe |
| EEG | Electroencephalography |
| ESA | Epilepsy South Africa |
| ESF | Epilepsy Support Foundation |
| FGD | Focus Group Discussion |
| FODPZ | Federation of Disabled Persons in Zimbabwe |
| GDP | Gross Domestic Product |
| GCAE | Global Campaign Against Epilepsy |

| | |
|---|---|
| HIV | Human Immunodeficiency Virus |
| IASW | Irish Association of Social Workers |
| IBE | International Bureau for Epilepsy |
| ICF | International Classification of Functioning, Disability and Health |
| IFSW | International Federation of Social Workers |
| ILAE | International League Against Epilepsy |
| ILO | International Labour Organisation |
| MRCZ | Medical Research Council of Zimbabwe |
| MRI | Magnetic Resonance Imaging |
| NASCOH | National Association for the Care of the Handicapped |
| NDB | National Disability Board (disability board) |
| NEC | National Employment Council |
| NGO | Nongovernment organisation |
| NSSA | National Social Security Authority |
| RCZ | Research Council of Zimbabwe |
| RSM | Registered Spirit Medium |
| RTMP | Registered Traditional Medical |
| SADC | Southern Africa Development Community |
| SAFOD | Southern Africa Federation of the Disabled |
| SINTEF | Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology |
| SDGs | Sustainable Development Goals |
| UN | United Nations |
| UNDP | United Nations Development Program |
| UON | University of Newcastle |

| | |
|---|---|
| UPIAS | Union of the Physically Impaired Against Segregation |
| WHO | World Health Organisation |
| ZIMDEF | Zimbabwe Manpower Development Fund |
| ZIMSEC | Zimbabwe Schools Examination Council |
| ZINATHA | Zimbabwe National African Traditional Healers' Association |
| ZLAE | Zimbabwe League Against Epilepsy |
| ZIPAM | Zimbabwe Institute of Public Administration and Management |
| ZSA | Zimbabwe Statistics Agency |

# Non-English words

## Words used in Zimbabwe

| | |
|---|---|
| *ChiKirisitu* | Christianity |
| *Chisingarapike* | Not medically treatable |
| *Chivanhu* | Indigenous religion |
| *Gombwe* | Ancestral medium |
| *Izifafa* | Epilepsy in Ndebele language |
| *Jambwa* | Curse |
| *Kutyisa* | Fearsome |
| *Mamhepo* | Evil spirit or demons |
| *Mashavi* | Individual spirits or talents |
| *Mhondoro/Sadzinza* | Spirit medium for a clan |
| *Munyama* | Bad luck or misfortune |
| *Mwari* | Shona name for God (also known as *Musikavanhu* or *Nyadenga)* |
| *N'anga/Sangoma* | Traditional spiritual or herbal healer |
| *Ngozi* | Avenging spirit |
| *Pfari* | Epilepsy |
| *Shona* | Language of the Shona people |
| *Svikiro* | Local spirit medium |
| *Tsikamutanda* | Witch hunter |
| *Ubuntu* | Humanness in Zulu language |
| *Ukama* | State of being related |
| *Umlimu* | God in Ndebele language |
| *Unhu* | Humanness in Shona language |

| | |
|---|---|
| *Uroyi* | Witchcraft |
| *Vadzimu* | Ancestors |
| *Zvikwambo* | Goblins (singular *Chikwambo*, also known as *zvidhoma*, *tokoroshi*, or *zvishiri)* |

## Words from other countries

| | |
|---|---|
| *Jinn* | Evil spirits or demons in Arab language |
| *Fquih* | Islamic religious scholar |
| *Jadu/dua* | Witches in Afghanistan |
| *Jadugar* | Magicians in Afghanistan |

# Abstract

This qualitative study examined employment barriers for people with epilepsy, a non-communicable neurological condition characterised by recurrent seizures. Although epilepsy treatment is usually successful with antiepileptic medication, misconceptions about epilepsy in society and long-term social stigma often leads to social exclusion, with epilepsy being viewed as a disability.

The exclusion of people with disabilities from employment results in huge socioeconomic costs to society. As in many other countries in the Global South, where public services are less than ideal, people with epilepsy in Zimbabwe encounter difficulties in obtaining social support and employment assistance. This study revealed the social injustices experienced by people with epilepsy, which resulted in complex barriers to employment. Nancy Fraser's theory of social justice, which situates injustice in the economic, cultural/legal, and political domains, was used to understand injustices as they related to disability and employment. Further, a systematic review of the literature revealed that most researchers viewed epilepsy from an individualistic rather than structural perspective, treating it as a biomedical rather than a social condition. Accepting the biomedical approach to treatment, this study employed a social model of disability to focus on the social injustices endured by people with epilepsy due to ignorance-induced social stigma.

This qualitative study used 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. Participants comprised of 13 females and 17 males with a mean of 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. The service providers included two health workers, three social service workers, and two advocacy workers. The two

datasets were analysed separately using NVivo, a computer-assisted, qualitative data-analysis package. The analysis showed that factors that influenced employment related to: (i) prevalent beliefs about epilepsy; (ii) inadequate public services; (iii) competitive job-seeking and workplace environment; and (iv) the self-management strategies used. These findings highlighted the structural barriers leading to poor employment outcomes for people with epilepsy, including poor public services and cultural and religious beliefs that fostered misconceptions about epilepsy, negative social attitudes, stigma-related fear and exclusion, compromised education and vocational training, sustained ineffective traditional interventions, and delayed medical treatment. Faced with these social barriers, effective self-management strategies enabled some participants to achieve better employment outcomes than others. A comprehensive epilepsy-management model was proposed. The model suggested increased formal and informal social support, healthcare, public education, advocacy, and employment services provision to enhance the employment participation of people with epilepsy and achieve their greater social inclusion.

# CHAPTER 1

# Introduction to the study

This introductory chapter provides the background to, and rationale for, the study and discusses the major concepts and issues that informed the research − social justice, employment, and disability. This is followed by an elaboration of the nomenclature used and an outline of the structure of the thesis.

## Background to the study

This qualitative study explored employment barriers for people with epilepsy, a non-communicable neurological condition characterised by recurrent seizures. Although epilepsy treatment is usually successful with antiepileptic medication, misconceptions about epilepsy in society and long-term social stigma often leads to social exclusion, with epilepsy being viewed as a disability. Despite the excessive socioeconomic costs of excluding people with disability from economic participation in Zimbabwe, little attention has been given to the structural factors preventing them from engaging in gainful employment.

The WHO (2011) estimated the prevalence of disability to be 15% or over a billion people worldwide, of which 100 million were living in Africa. Of these, about 800 million or 80% were of working age (ILO, 2015). Based on WHO (2011) estimates, there were approximately 1.8 million people with disabilities in Zimbabwe. Of these, close to 1.5 million were of working age. However, Mtetwa (2011) warned that estimates of the prevalence of disability in Zimbabwe were highly contentious with figures varying across studies, due to inconsistent definitions and methods measuring prevalence. For example, a n UNICEF (2013) survey reported a national prevalence of 7%, far below the WHO's (2011) estimates.

Despite laws prohibiting workplace discrimination, people with disabilities of working age often found themselves unable to acquire and maintain jobs leading to socioeconomic loss for individuals, families, communities, businesses, and nation states (ILO, 2013, 2017). Based on research from ten low- and middle-income countries, including Zimbabwe, the ILO (2015) estimated that the economic cost of disability exclusion was between 3-7% of Gross Domestic Product (GDP) worldwide. This form of injustice contributed to poverty among people with disabilities and represented a huge socioeconomic loss that could not be ignored (ILO, 2017). To address this injustice, studies were needed to highlight the factors preventing the economic participation of people with disabilities like epilepsy.

## Rationale for the study

While attending the International Epilepsy Conference in Kampala, Uganda on October 17, 2005, the researcher heard a story on the employment experience of a person with epilepsy that caught his attention. During one of the conference sessions, Berna Mwenje (not his real name) stood, uninvited, in front of government officials, including ministers of health and social development, and international delegates from Denmark and several African countries, and bravely declared:

> I have lived with epilepsy the whole of my life. As I stand before you, I possess not only a degree in law but a diploma in accounting. My law degree was granted by Makerere University, one of Africa's top universities, several years ago. However, since I qualified, I have failed to secure permanent employment and, when I secured it, it slipped away without me even noticing it. Currently, I am out of employment. Selling newspapers has been my new work for the last six months, what else can I do in this world full of stigma? [Paraphrased based on original event].

Sobbing, he was unable to finish his story. There followed a deafening silence and, in the face of his interjection, the discussion on the progress of the African Declaration on Epilepsy seemed to pale into insignificance. With Berna's declaration, theory met reality, so it became a moment of reflection for the delegates. Berna had succinctly described the consequences of stigma encountered by people with epilepsy in Africa, especially Zimbabwe, the context with which the researcher was most familiar.

This research sought to explore the structural barriers preventing people with epilepsy in Zimbabwe from gaining and maintaining employment. At a broader level, it sought to explore the social injustices this group endured through the lens of Nancy Fraser's (2001, 2008, 2009) theory of social justice. It sought to contribute to an under-researched area of study in Zimbabwe, where people with epilepsy are all too frequently ignored in policy and service provision. The economic effects of epilepsy had not, heretofore, been studied in Zimbabwe. Most research on epilepsy in Zimbabwe, for example, Ball and Taderera (2003) and Madzokere (1997) examined the biomedical and psychological aspects of this neurological condition. Consequently, epilepsy management focused on the biomedical treatment of individuals and neglected the socioeconomic factors like income-earning capacity, financial stressors, employment opportunities, and sustainable livelihoods.

In the interests of social justice, this research studied the broader factors and social injustices encountered by people with epilepsy, when seeking appropriate treatment, education, employment, and social support. By doing so, the research contributed to knowledge in two main ways: re-framing the understanding of epilepsy from an individual to a broader social perspective and offering a social justice informed epilepsy-management model to help with policy development and social work education and practice. Key concepts and issues guiding the study are described in the next section, beginning with the concept of social justice.

**Key concepts and issues guiding the study**

*Social justice*

There are varying philosophical perspectives on social justice (UN, 2006b). These perspectives include John Rawls' (1971, 1999) on distributive justice, Amartya Sen's (1985) on capabilities, Charles Taylor's (1994) on recognition, Honneth's (1994) on recognition, and Nancy Fraser's (2001, 2008) on economic, cultural/legal, and political factors giving rise to injustice. This study adopted Nancy Fraser's conception of social justice because of its attention to broader structural factors. For Fraser, social injustice arose from economic inequalities, social class insubordination, cultural/legal restrictions, and the political voicelessness of marginalised groups, which, in turn, called for redistribution, recognition, and representation, respectively, as discussed in Chapter 3.

Though social justice is a broad concept, there are specific examples of its practical application internationally and in Zimbabwe. The Charter of the United Nations and Statute of the International Court of Justice, Universal Declaration of Human Rights, and the International Covenant on Civil and Political Rights (UN, 1945, 1948, 1966). These early policy instruments established the universal human rights framework adopted by democratic nation states worldwide (UN, 2006b) and reinforced by subsequent agreements, including the Copenhagen Declaration and Programme of Action (UN, 1995) and Millennium Declaration (UN, 2000), and the establishment of international organisations to advance human rights, such as the Human Rights Council (HRC), World Health Organisation (WHO), and International Labour Organisation (ILO). The Constitution of Zimbabwe contains a charter of human rights to support its pursuit of social justice and the country adopted the CRPD in 2013 (UN, 2006a), along with the regional and national policy protocols discussed in Chapter 5, to achieve social justice for disadvantaged populations, including persons with disabilities. In traditional

Zimbabwean society, prior to constitutionalism, justice was reflected mainly in the philosophies and practice of *unhu* (Shona language) or *ubuntu* (Zulu language), meaning common humanity and *ukama*, meaning relations (Murove, 2007; Samkange & Samkange, 1980; Shava, 2008). Though the value of *unhu* has dwindled, it conveys the idea that humans are human because of others, through solidarity, human relationships, and mutual obligation (Samkange & Samkange, 1980; Tutu, 1999).

## *Employment*

The term employment, and its affiliates work, income, job, labour market or economic participation, and livelihood, as defined by the ILO (2007), does not necessarily refer to formal paid work, but also includes informal unpaid or self-help jobs, unpaid domestic work, and individual businesses or microenterprises. The ILO has long distinguished between paid work and self-employment (or informal work) (ILO, 1993) seeing both as important for economic empowerment (ILO, 2007). Paid employment involves oral or verbal contracts and a basic income (salary or wage or, at times, commissions and bonuses), or in-kind payments not dependent on the revenue of the employer, and self-employment work, where remuneration accrues from profits from the sale of goods or services (ILO, 1993). The ILO (1993) defined employed people as:

> Persons who during a specified brief period such as one week or one day, (a) performed some work for wage or salary in cash or in kind, (b) had a formal attachment to their job but were temporarily not at work during the reference period, (c) performed some work for profit or family gain in cash or in kind, (d) were with an enterprise such as a business, farm or service but who were temporarily not at work during the reference period for any specific reason (p. 47).

The ILO (2016) argues for 'decent work' in the formal and informal economies, that is, work that enables people to survive and develop, and live quality lives. Decent work affords people a minimal wage of more than USD2 a day and can lift people out of poverty (ILO, 2016). For many people, however, work is anything but decent. It pays a meagre income for those for whom poverty continues unabated. The SDGs seek to increase the number of jobs and promote decent work by 2030 (UN, 2015). SDG8 aims to 'promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all' (UN, 2015, para.1).

## *Disability*

The CRPD (UN, 2006a) defines persons with disabilities as including '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' (UN, 2006a, p. 2). The strengths of the UN's definition of disability lies in its broader view of impairments and inclusion of intellectual disabilities that had not been recognised previously, its focus on barriers, and emphasis on participation. It likely built on the WHO's (2001) earlier definition:

> [Disability is] an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (p. iii)

The WHO definition embraces medical and previously neglected psychosocial views of disability. While both the UN and WHO definitions are broad and emphasise person-environment interactions, Zimbabwe's official definition of disability in the Constitutionally supported Disabled Persons Act (Government of Zimbabwe, 1992) has a person-centred focus:

[A disabled person is] 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 (p. 1).

Although the Zimbabwe constitution does not have a separate definition of disability, it refers to persons with physical and mental disabilities and has provisions to avoid discrimination against disabled people and provide welfare support for them. In specifying impairments, the Zimbabwean definition omits intellectual disabilities and its wording 'which gives rise to … barriers' misleadingly implies the barriers result from the person's disability and not society's approach to disabled people. Though the UN and WHO definition draws attention to the person-in-environment, their focus is also individualistic: the negative aspects of the interaction between an individual and the environment surrounding that individual. The Zimbabwe definition has given rise to a medical treatment model (Mtetwa, 2011) that fails to address broader social issues, such as the widespread poverty among people with disabilities.

## Nomenclature

Accepted nomenclature varies widely and changes from one decade to the next. The researcher chose to use the term 'people with disability or disabilities' rather than 'disabled people', and 'people with epilepsy' rather than 'epileptics' or 'epileptic people'. The terms 'disabled person' and 'person with disability' are widely used in disability work, though there is no consensus on which is most appropriate. People often use the term disabilities as a reminder of the diverse forms of disability present in society (Noble & Marson, 2016). The Disabled Persons Act (Government of Zimbabwe, 1992) uses the term 'disabled people', while the CRPD (UN, 2006a) uses the term 'person with disability'. Authors in disability work vary in their choice

of terms. For example, Simcock and Castle (2016) used 'person with disability' (person-first language) and Oliver (2013) used 'disabled people'. 'Person with disability' puts the person, not the disability, first (person-first and not disability-first language) (Noble, Robinson, Snape, & Marson, 2017). Research involving 'patients' and carers showed they preferred person-first language (Noble & Marson, 2016). Noble et al. (2017) viewed the term 'disabled person' as insulting and discriminatory.

## Structure of the thesis

Chapter 1 outlined the background and rationale for the study and discussed the key concepts and issues guiding the research, namely, social justice, employment, disability, and epilepsy. Chapter 2 reviews contemporary knowledge on epilepsy and its management. Chapter 3 outlines the theoretical framework undergirding the research, notably social justice. Chapter 4 reviews and discusses the literature on employment of people with disability. The Zimbabwean context in which the study was conducted is the subject of Chapter 5. Chapter 6 presents the qualitative methodology employed. The study's findings are presented in Chapters 7 (people with epilepsy) and 8 (service provider perspectives). The final chapter (Chapter 9) discusses the findings, conclusions, and implications of the study and offers suggestions for future research.

## Conclusion

This chapter introduced this study on employment barriers for people with epilepsy in Zimbabwe, where, as in many other countries in the Global South, people with disability encounter stigma-related social exclusion and poverty. As subsequent chapters show, there was a dearth of literature on issues relating to the employment of people with epilepsy in Africa, including Zimbabwe, hence the need for this study. This chapter introduced key concepts

informing the study – social justice, employment and disability and the choice of person-first language – 'people with epilepsy' and 'people with disabilities'. With adequate treatment and support services, epilepsy need not be disabling. However, in this research, epilepsy was framed as a disability owing to the multiple disabling factors that are not addressed in Zimbabwe, and most countries in the Global South. The thesis is presented in nine chapters. The chapter that follows reviews contemporary knowledge on epilepsy.

# CHAPTER 2

# Contemporary knowledge on epilepsy

This chapter reviews contemporary knowledge on epilepsy. It discusses the causes, symptoms, and prevalence of epilepsy before reviewing traditional and modern understanding of the condition. It discusses four broad perspectives of understanding and managing epilepsy: traditional/religious, biomedical, psychosocial, and disability. Erving Goffman's seminal work on stigma is discussed under psychosocial perspectives. The chapter ends with a discussion of epilepsy management in Zimbabwe.

## Causes, symptoms, and prevalence

Epilepsy is a chronic, non-communicable brain condition characterised by recurrent seizures and long-term social stigma (Baskind & Birbeck, 2005a; Leaffer, Hesdorffer, & Begley, 2014; Shorvon, 2009; WHO, 2016). Medically, seizures are known to emanate from neurons in the brain, the nerve cells responsible for communication between the brain and the body, through the transmission of electrical impulses (Shorvon, 2009). A disturbance in this transmission process may result in an excessive discharge of 'messages' with body parts 'failing to take orders'. 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, 2004a). There are numerous causes of brain damage, including a lack of oxygen to the brain, head trauma at birth or due to accidents, substance – drug or alcohol – abuse, brain tumours, infections, such as meningitis, and genetic syndromes. Most of these causes are preventable.

Seizures are classified as focal, generalised, or of unknown origin (Fisher et al., 2016). Focal seizures, previously termed partial seizures, start from a localised part of the brain and they usually affect a small part of the body, while generalised seizures are widespread throughout the brain and, therefore, usually affect the whole body (Fisher et al., 2016). As the name suggests, unknown origin denotes inability to diagnose the cause of seizure onset. Seizures are characterised by stiffening body muscles (tonic), or not (atonic), jerky movements (clonic), or a combination of these (tonic-clonic, formerly *grand mal* seizure) (Kiriakopoulos & Shafer, 2017). Some seizures involve loss of consciousness, formerly referred to as absence or *petit mal* seizures (Fisher et al., 2016). Seizures usually last one to three minutes. Those exceeding five minutes are treated as medical emergencies (Kiriakopoulos & Shafer, 2017; Shorvon, 2009). Following a seizure, a person may become confused, drowsy, or depressed (Kiriakopoulos & Shafer, 2017). Some seizures are accompanied by groaning, jerking, cries, sudden falling, biting of the tongue, urinating, or other acts that are often unpleasant to experience or witness (Kiriakopoulos & Shafer, 2017).

Epilepsy requires life-long treatment with daily doses of antiepileptic medication or, in some cases, brain surgery. Other treatment approaches include a ketogenic diet and vagus-nerve and deep-brain or trigeminal nerve stimulation (IBE, 2014). Non-Western treatments for epilepsy, often termed complementary, alternative, or nonconventional, include acupuncture, faith healing, religious and cultural practices, herbal remedies, homeopathy, aromatherapy, and Chinese medicine (IBE, 2014). Uncontrolled epilepsy temporarily or permanently limits daily activities, such as speech, mobility, memory, sensation, and social interaction (Birbeck & Kalichi, 2003).

Control of epilepsy seizures has improved with advances in medicine that has significantly increased the number of people with epilepsy living seizure-free, productive lives. Shorvon (2009) reported that, with medical treatment, 60% had been found to be seizure free

within five years and 50% would have their epilepsy fully controlled to an extent that they could cease their antiepileptic medication; only about 30% of people with epilepsy in the Global North required regular medical attention, while 65% required occasional attention. Though the effectiveness of medical treatment is well-established, research showed that 30% of people with epilepsy lacked effective treatment (Ferguson, 2012). Despite affordable treatment for epilepsy, most people with the condition in resource-poor settings were not properly diagnosed or treated (Baskind & Birbeck, 2005a; Shorvon, 2009). This created a medical treatment gap ranging from 25-100% in these communities (Newton & Garcia, 2012):

> This gap results from several factors including belief systems that attribute epilepsy to supernatural rather than medical causes, a dearth of health care facilities, health care workers who receive inadequate training in epilepsy diagnosis and care, and the substantial direct and indirect costs of care seeking (Baskind & Birbeck, 2005a, p. 1).

The WHO (2016) reported that epilepsy affected between four to 14 people per 1000, an estimated 50 million people worldwide. Though the most common neurological condition globally (Shorvon, 2009; WHO, 2005, 2016), epilepsy is more prevalent in the Global South, where 80% of people with epilepsy reside, perhaps 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).

The population of people with epilepsy in Zimbabwe was unknown, though estimates put the figure at between one and two percent (ESF, 1992; Saburi, Mapanga, & Mapanga, 2006). Mielke and Madzokere (2005) found a prevalence of 1.3% in a survey of the Hwedza District, which they conducted as part of the WHO-supported Global Campaign Against Epilepsy (GCAE). If the findings of this survey were generalised to the Zimbabwean population, one might expect an estimated prevalence of 169,000 people with epilepsy in a population of 13 million, i.e., 1.3%. A national survey reported a disability prevalence of 7%,

of which 2% of those surveyed had epilepsy (UNICEF, 2013). A more recent study at Karanda Mission Hospital showed that epilepsy constituted 2.8% of hospital attendance during the period of the study (Vyas, Wong, Yang, Thistle, & Lee, 2016). The ESF believed approximately 500,000 people were living with epilepsy in 2014, of which 353,000 (71%) were women and 300,000 (60%) were children but these estimates were not substantiated (Vinga, 2014).

## The understanding and management of epilepsy

Models for managing epilepsy include traditional/religious, medical, social, psychosocial, and disability perspectives. These are discussed in turn.

### *Traditional and religious perspectives*

In the religious era, epilepsy was seen to have supernatural causes, signalling divine punishment or demonic possession (Devinsky & Lai, 2008; Magiorkinis, Diamantis, Sidiropoulou, & Panteliadis, 2014). In Sweden and Norway, epilepsy was strange, mysterious, and caused by 'hidden people inhabiting the woods and the mountains' (Tuft, Nakken, & Kverndokk, 2017, p. 104). Treatment involved extracting the blood of criminals or itinerants with epilepsy or passing them through a hole in the sand to transfer the disease into the ground. As early as 400 BC, Hippocrates argued that epilepsy was a natural condition treatable with herbal or chemical substances, surgery, and diet but his theory was not widely accepted until after the 1850s (Magiorkinis et al., 2014).

Due to fear of contagion, people with epilepsy were ostracised from the community and tied to trees in the forest, or, as in Zimbabwe, chained to posts or committed to mental institutions, or, in communities where epilepsy was viewed as a curse, people with epilepsy were killed (ESF, 1992). Research showed that Zimbabweans saw epilepsy as a supernatural condition inflicted by *vadzimu* (ancestors), *ngozi* (evil spirit), or witchcraft (Gelfand, 1973;

Levy, Forbes, & Parirenyatwa, 1964). Other explanations of epilepsy among the Shona included that seizures followed the phases of the moon, were genetic, or resulted from objects in the stomach (ESF, 1992). Officials of the Shona religion, the *n'anga* (prophets, healers, or seers) and *mhondoro* (spirit mediums) healed through inhalations, exorcism, rituals, incisions, or body washing, then and now (Gelfand, 1973, 1974; Shoko, 2013). This situation existed in most parts of Africa, dominated by African traditional religion (Baskind & Birbeck, 2005a; Levy, 1970; Ndoye et al., 2005).

Various terms are used to describe traditional methods (WHO, 2000). These include indigenous (for those not influenced by external religions), cultural (those imbedded in local culture), and religious (those imbedded in local, Christian or Islamic religious beliefs). In this study, the author opted for the collective 'traditional' to refer to indigenous, cultural, and religious perspectives. Indigenous and religious theories view epilepsy as a supernatural condition caused by spiritual forces (Baker, 2002, Devinsky & Lai, 2008; Ferguson, 2012; Mushi, Hunter, Mtuya, Mshana, Aris, & Walker, 2011). Both regard epilepsy as a contagious spiritual condition with supernatural causes treatable through cultural or religious practices − sometimes termed complementary or alternative therapies (CAMs) − and not through conventional biomedical methods (Green, 2000). In many cultures, spiritual perspectives have proved impervious to biomedical advancements (Mushi et al, 2011; Mutanana & Mutara, 2015; Quereshi, Standing, Swai, Hunter, Walker, & Owens, 2017; Winkler et al., 2009).

*African indigenous and cultural perspectives*

Indigenous cultural beliefs − referred to as *Chivanhu* in some parts of Zimbabwe − sustain superstitions about epilepsy in Zimbabwe (Devlieger, Piachaud, Leung, & George, 1994; Mutanana & Mutara, 2015; Shoko, 2013). Despite the arrival of Christian and Islam missionaries in the 15th century, indigenous beliefs remained a key pillar of traditional Zimbabwean society. God was seen to be working through traditional healers − *n'anga*,

14

*sangoma,* or *chiremba* – lending support to their faith-healing interventions (Andersson, 2002; Madzokere, 1997; Mutanana & Mutara, 2015; Vinga, 2014).

In Zimbabwe, epilepsy is known as *pfari* (Shona) and *izifafa* (Ndebele) (Vinga, 2014) and is linked to zv*ikwambo* (singular *chikwambo*), meaning goblin (also referred to as *zvidhoma, tokoroshi*, and *zvishiri*.), an evil or mischievous spirit; a playful or malicious elf; a frightful phantom; or a gnome. A *chikwambo* is an object imbued with magical powers that *n'angas* (traditional healers) sell to people who believe that they will get rich quickly. Dube, Shoko, and Haves (2011) explained that *zvikwambo* were often made of human body parts so the purchaser was usually urged to keep it secret, from family members, or within the family. Their continued efficacy depended on sacrifices, which became increasingly onerous and, in rare instances, included human sacrifice. People regarded the act of acquiring a *chikwambo* as witchcraft and believed that the ancestors or God would punish those who acquired riches in this evil way. *Zvikwambo* might be objects of misfortune or inexplicable riches, the latter attached to success stories or myths in Zimbabwean cultural tradition. To some, a *chikwambo* is the spirit of a dead person brought to life to slave for its owner. To others, it is an inanimate object that can transform into any creature. Other terms used are goblins, *zvidhoma*, *tokoroshi*, and *zvishiri.*

Traditional healers use various methods of spiritual healing in Zimbabwe. A popular method involves finding the witch responsible for supernatural interference and destroying her medicines or goblins by performing a spiritual ritual 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 (ESF, 1992; Mutanana & Mutara, 2015). Herbs might be swallowed, inhaled, or inserted 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 stay for treatment. Methods of treatment similar to those in Zimbabwe have been reported in Uganda, Tanzania, Malawi, Morocco, South Africa, and Zambia (Baskind & Birbeck, 2005a, 2005b; Birbeck, 2000; Duggan, 2013; Ferguson, 2012; Keikelame & Swartz, 2015; Mushi et al., 2011; Watts, 1989; Winkler et al., 2009). In most of these countries, epilepsy was linked to witchcraft, curable only by traditional healers. In Malawi and South Africa, traditional healers claimed to treat the spiritual cause of epilepsy but agreed some types of epilepsy required medical treatment (Keikelame & Swartz, 2015; Watts, 1989).

In Zimbabwe, indigenous beliefs were institutionalised through the Traditional Medicinal Practitioners Act (Goverment of Zimbabwe, 1981), Witchcraft Suppression Act (Goverment of Zimbabwe, 1918), and the Zimbabwe National African Traditional Healers' Association (ZINATHA), which was formed in 1980. However, despite efforts to improve traditional healing practices, they remain under researched, under regulated, and ineffective. Most importantly, indigenous beliefs have led to the denial of medical treatment for people with epilepsy, who pay huge sums of money for ineffective traditional remedies. Green (2000) found many people with epilepsy in the Global South spent time and resources on traditional remedies, since they considered the 'treatment of seizures … the domain of traditional healers' (p. 805).

## Christian perspectives

In Zimbabwe, Christian beliefs varies across Catholic, Protestant, Pentecostal, and African churches though most religious adherents saw epilepsy as a punishment from God, a testing of one's faith by God, or a curse from an avenging evil spirit or witch (Chavunduka, 1986; Jackson & Mupedziswa, 1988; Mutanana & Mutara, 2015). The treatment of epilepsy varied, though most churches advised adherents to have faith in God, read the bible, fast, pray, and seek

healing from prophets, who used anointing oils, water, stones, and touch to heal the patient. Some churches entreated patients to wear bracelets with bible verses on them or a piece of cloth around the waist. In the past, prophets received tokens of appreciation, though nowadays they charged huge fees. Some religious healers ran profitable shrines and retreats. Present-day prophecy in Zimbabwe is promoted through public television, where spiritual healers advertise their services and successes, and people are easily attracted to charismatic prophets, who permit diverse forms of payment, including church partnership or consultation fees; many advertised and sold lucrative anointing oils, holy water, towels, bangles, bracelets, or other items thought to have healing powers (Chitando, Gunda, & Kügler, 2013). In the Pentecostal and African churches, this had become a huge business with some patients travelling to other African countries for spiritual healing (Chitando et al., 2013). Acceptance of medical treatment varied among Christian churches. The oldest African churches did not subscribe to medical treatment for spiritual conditions, though newer churches condoned the medical treatment of epilepsy (Shoko, 2013). Studies in other African countries observed similar beliefs and practices (Atadzhanov, Chomba, Haworth, Mbewe, & Birbeck, 2006; Mushi et al., 2011; Quereshi et al., 2017; Winkler et al. 2009).

*Islamic perspectives*

In the Islamic religion, illness is a test of one's faith in Allah or an atonement for past sins (Al-Adawi et al. 2003; Almutairi, Ansari, Sami, & Baz, 2016; Daber-Taleh, Uwe, & Rösche, 2017; Mughees, 2006). Sickness was 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). Though God is their ultimate spiritual healer, Muslims, condone medical intervention (Ferguson, 2012). Zimbabwe's Muslim population is small. In Morocco, which has a majority Muslim population, epilepsy was a religious, supernatural, and cultural condition caused by evil spirits or demons called *jinn* (Ferguson, 2012). *Jinn* was

reported in other Muslim countries, such as the Kingdom of Saudi Arabia (Almutairi et al., 2016) and Afghanistan (Daber-Taleh et al., 2017). A *fquih* or an imam, a religious scholar well-versed in the Quran, used his supernatural powers to speak with, and expel, the *jinn,* while touching the patient. If this did not work, the *fquih* recited passages from the Quran or treated the 'possessed person' with smoke and scents. Sick people often wore charms and amulets with Quran verses on them to stave off evil. If none of these rituals worked, this meant the *jinn* had married the patient, parented children, and was unwilling to leave. To prevent evil possession, people had to 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). Witches, or *jadu/dua* were considered a possible cause of epilepsy in Afghanistan's traditional *shamanist* belief system (Daber-Taleh et al., 2017). Besides imams, magicians called *jadugar* treated epilepsy in Afghanistan though medical treatment was also condoned (Daber-Taleh et al., 2017). Resultantly, as in traditional African societies, the treatment of epilepsy in Islamic societies combines medical and spiritual methods (Almutairi et al., 2016; Daber-Taleh et al., 2017; Ferguson, 2012).

## *Biomedical perspective*

Around the 1850s, researchers Hitzig and Todd described the electrical theory of epilepsy (Magiorkinis et al., 2014). Though herbal treatment continued, Sir Locock discovered the usefulness of potassium bromide in the treatment of epilepsy in 1857, which remained popular until the discovery of phenobarbital in 1912 (Magiorkinis et al., 2014). The electrical theory of epilepsy and the classification of epilepsy into idiopathic or sympathetic and petit or grand mal seizures became widely accepted (Magiorkinis et al., 2014).

In the 1930s, Hans Berger proved that epilepsy arose from electrical activity in the brain and used that information to invent the electroencephalography (EEG), followed by the discovery of the first drugs for the treatment of epilepsy around 1940, though these early

medicines had many side effects (Ferguson, 2012). Ongoing pharmacological research resulted in the effective and affordable medicines used today. Several methods of treatment for severe epilepsy developed, including surgery, though medication remained the primary treatment for more than 70% of epilepsy cases (Ferguson, 2012). Despite advances in medicine, including diagnostic and surgical equipment, there was still no complete cure for seizures, with most people with epilepsy remaining on life-long, daily medication to control their seizures. Medicines are often classified as first-, second-, or third-line, with the latter most effective but expensive (WHO, 2016). Even if fully treated, some people with epilepsy were susceptible to seizures triggered by, inter alia, fatigue, light, heat, hormonal changes due to pregnancy, menstruation, or aging, and lack of sleep or food (Dekker, 2002). Moreover, even with the advent and development of antiepileptic medication, several communities continued to rely on herbal remedies and spiritual healing, while prejudice against people with epilepsy remained in most countries (Ferguson, 2012).

Medically, epilepsy is a biological condition resulting from temporary or permanent impairments of the brain or its components that can be corrected with antiepileptic medication or surgery (WHO, 2015). The discovery of potassium bromide in 1857 strengthened the medical model (Scott, 1992). Supported by scientific research, medical treatment became the most effective method of seizure control in Africa, as elsewhere. In Malawi, Watts (1989) reported that after six months of medical treatment, 40 (56%) of 71 patients had been fully controlled, while 20 (28%) had greatly improved. Following this success, Watts (1989) developed an eight-stage model for epilepsy management in settings like Malawi, as shown in Table 2.1. The model aimed to balance treatment 'efficacy with simplicity of use' (Watts, 1989, p. 807) in resource-poor settings in Africa. Watts' (1989) epilepsy-management model has these eight elements:

1. Adequate publicity about the availability of treatment.

2. Education of both staff and patients.

3. A simple treatment regimen, based on phenobarbitone.

4. Maintaining an adequate supply of drugs.

5. Treatment without charge.

6. Monthly clinics to review patients.

7. Ensuring that each month the patient is reviewed by the same member of staff.

8. Mobile clinics to make treatment more accessible.

Based on this model, Watts (1989) increased the number of people on epilepsy treatment in Malawi from 71 to 3000 and treatment units increased from one to 45. Most of the patients had spent six and a half years, on average, without medical treatment. Internationally, medical progress has advanced the treatment of epilepsy though the Global Campaign Against Epilepsy (de Boer, 2010; de Boer, Engel Jr., & Prilipko, 2005; ILAE, WHO, & IBE, 2000). While the medical model made strides in seizure control, it failed to address the structural conditions relegating people with epilepsy to the lowest rungs of society (Baskind & Birbeck, 2005a, 2005b; de Boer, 2010; Newton & Garcia, 2012; Shorvon, 2009). As yet, antiepileptic medicines have not been made adequately available and affordable in developing countries and treatment facilities are overstretched and under resourced (Adamolekun & Meinardi, 1990; Baskind & Birbeck, 2005a; Meinardi, Scott, Reis, & Sander, 2001).

The cost for medical management of epilepsy was found to be very low. A study of poor countries found that the cost was USD25 per person per year (Birbeck, Chomba, Mbewe, Atadzhanov, Haworth, & Kansembe, 2012). This included the cost of training healthcare workers, first-line medicines, and related costs. The cost of epilepsy medicines was lower than that for other chronic conditions (Birbeck et al., 2012). In India, Megiddo, Colson, Chisholm, Dua, Nandi, and Laxminarayan (2016) estimated that USD5 was required to provide essential epilepsy medicines per person per year. However, this low cost has not resulted in increased

government support for epilepsy (Birbeck, 2011; Birbeck et al., 2012; Kvalsund & Birbeck, 2012). In fact, the treatment gap in poor countries remains very high.

## *Psychosocial perspectives*

Psychological aspects that include depression, anxiety, stigma, and low self-esteem (Baker, 2002; Dekker, 2002; Tai, 2011). The important addition was the recognition of the need for social measures – social policy, social services, social care, and social support – for people with epilepsy. Most importantly, it recognises the structural factors that result in stigma, discrimination, marginalisation, and exclusion of people with epilepsy (Dekker, 2002; Mugumbate, Riphagenn, & Gathara, 2017) and seeks to address the sociocultural, 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 that is sometimes more difficult to overcome than the seizures (Dekker, 2002; Elger & Schmidt, 2008; Mugumbate et al., 2017).

The psychosocial model has been promoted by the WHO's (2001) International Classification of Functioning, Disability and Health framework. The International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) have expanded the biopsychosocial model through their UN consultative status and affiliates in more than 100 countries (de Boer, 2010). The ILAE was formed in 1909 to advance prevention, diagnosis and treatment of epilepsy (ILAE et al., 2000). The IBE (2014) was formed in 1961 to ensure recognition of epilepsy in health and research and the protection of the rights of people with epilepsy. Together with the WHO, these two organisations embarked on the Global Campaign Against Epilepsy. They introduced International Epilepsy Day in 2015 and the WHO (2015) Resolution on Epilepsy to strengthen global care for epilepsy and advance the rights of people with epilepsy. Delegates at the World Health Assembly endorsed the Resolution on the Global Burden of Epilepsy and urged member states to strengthen their ongoing efforts to provide

healthcare for people with epilepsy (WHO, 2015). They advocated the adoption, funding, and implementation of policies, legislation, and national healthcare plans of action for epilepsy management; integration of epilepsy prevention and management into primary healthcare; establishment of research centres and training programs for nonspecialist healthcare providers; capacity building for people with epilepsy and their carers; improved access to and affordability of antiepileptic medicines; public education to reduce misconceptions about epilepsy; timely treatment; improved access to education and employment; collaborations with civil society and other partners; and awareness raising to reduce stigma and discrimination (de Boer, 2010; Dekker, 2002; Elger & Schmidt, 2008; Lancet, 2015; Tai, 2011).

*Stigma and Erving Goffman's seminal work*

Throughout history, people with epilepsy have endured stigma, prejudice, exclusion, and discrimination (WHO, 2016). For example, in the USA, owners of public spaces had the right to deny people with epilepsy access until the 1970s, and 1971 in the United Kingdom (UK) (WHO, 2016). In India, China, and many other countries, epilepsy provided grounds to annul a marriage (WHO, 2016). In other parts of the world, people with epilepsy were prevented from having children, while companies refused to hire people with epilepsy (WHO, 2016). However, around the 1990s, the social status of people with epilepsy changed in the USA, when Congress passed the nation's first civil rights law, the Americans with Disabilities Act (Government of USA, 1990), which included anti-discriminatory clauses for people with impairments of any nature. High levels of stigma have been reported in many African countries, including Zambia (Birbeck, 2000), Senegal (Ndoye et al., 2005), Kenya (Dekker, 2002), Zimbabwe (Dewa et al., 2014; Madzokere, 1997; Reis & Meinardi, 2002), Nigeria (Nuhu, Fawole, Babalola, Ayilara, & Sulaiman, 2010), Uganda (Duggan, 2013), Tanzania (Mushi et al., 2011), South Africa (Magazi, 2017; Wilmshurst, Kakooza-Mwesige, & Newton, 2014), and Malawi (Watts, 1989, 1992).

Erving Goffman (1963) paved the way for understanding the role of social stigma in society, which he defined as 'the situation of the individual who is disqualified from full social acceptance' (p. 9). Goffman (1963) delineated three types of stigma. The first arose from abominations of the body or physical deformities and the second from antisocial behaviours caused by:

> blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these inferred from known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour (Goffman, 1963, p. 14).

Abominations of the body resulted in felt stigma, a situation where people with epilepsy hid their condition, refused to disclose it in the community or at work, and failed to seek help (Amjad, Nasrabadi, & Navab, 2017; Dekker, 2002; Kilinc & Campbell, 2009; van Brakel, 2006). The third − tribal stigma − stemmed from the factors that made people different, such as race, nation, and religion. Resultantly:

> we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkably, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalising an animosity based on other differences, such as those of social class (Goffman, 1963, p. 15).

Directly referring to epilepsy, Goffman (1963) said:

> The epileptic subject to *grand mal* seizures provides a more extreme case; he may regain consciousness to find that he has been lying on a public street, incontinent,

moaning, and jerking convulsively − a discrediting of sanity that is eased only slightly
by his not being conscious during some of the episode (p. 106).

When people discriminate against and excluded people with epilepsy because of their their
condition, stigma is enacted (Kilinc & Campbell, 2009; Obeid, 2008). Goffman (1963) saw
stigma as a social construction, where society set the rules of acceptability and tolerance; those
that did not conform to the norm were stigmatised. Goffman (1963)'s theory resonated with
the social model of disability and the theory of recognition, discussed in Chapter 3. Labelling,
stigma, or misrecognition accrued to people with low socioeconomic status, or of lower castes
in some societies; people who belonged to certain religions; people of different races or genders
(Leaffer et al., 2014); or people with epilepsy or other health conditions (Elliott & Richardson,
2014; van Brakel, 2006).

The stigma model has received unparalleled attention in epilepsy studies (Amjad et al.,
2017; Baskind & Birbeck, 2005a, 2005b; de Boer, 2010; Kilinc & Campbell, 2009; Mushi et
al, 2011; Newton & Garcia, 2012; Obeid, 2008; Watts, 1989, 1992; WHO, 2016). Baskind and
Birbeck (2005b) described stigma as devastating burden on people with epilepsy. Epilepsy-
related stigma existed at a number of levels. First, people with epilepsy faced stigma due to the
erroneous belief that their condition was contagious and could be spread through saliva, faeces,
or urine. This reduced body contact, even when first-aid help was needed (Baskind & Birbeck,
2005b; Dekker, 2002). The child with epilepsy encountered stigma and discrimination, even in
their family, due to misconceptions about their condition. Secondly, families of people with
epilepsy were stigmatised by those who believed it was an evil condition inflicted on those
who had sinned (Amjad et al., 2017). Baskind and Birbeck (2005b) called this courtesy stigma.
Thirdly, professionals working with people with epilepsy might stigmatise. Some professionals
stigmatised people with epilepsy in receipt of traditional treatment and, in some cases, were
unwilling to treat them (Baskind & Birbeck, 2005b). In Zambia, and many other countries,

teachers stigmatised students with epilepsy and had reservations about people with epilepsy marrying or becoming employed (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2006). Zambian health professionals, too, stigmatised people with epilepsy (Chomba, Haworth, Atadzhanov, Mbewe, & Birbeck, 2007). Traditional healers played a major role, not only in treating people with epilepsy but also:

> By identifying socially inappropriate behavior (either of the person with epilepsy or people close to them) and interpreting this as the cause of seizures, they may be powerful enforcers of socially appropriate behavior. The practice of 'immunizing' the family members of 'PWE' against the perceived contagion may serve a protective function (Baskind & Birbeck, 2005b, p. 72).

Baskind and Birbeck (2005b) noted that 'fundamental theories of stigma … emphasize its important functional role as delineating between the normal and the deviant in society. The linking of epilepsy to deviant social behavior is a striking example of this premise' (p. 72).

Writers such as Hunt (1966) and Scambler, (2009) explained stigma from a social perspective as opposed to Goffman's largely personal tragedy or deviance view. Hunt's seminal collection on stigma and disability focused on the experiences of people with disability whilst Scambler (2009) focused on health-related stigma; arguing that initial discussions of stigma needs reframing to pay attention to structural factors as opposed to individual factors. For Scambler (2009, p. 453), 'stigmatisation can be infused with exploitation and oppression'. This reframed view of stigma aligns with the social justice theory and social model adopted for this study.

## *Disability perspectives*

There is debate on whether people with epilepsy are disabled (Calvert, 2011; Epilepsy South Africa (ESA), 2014). Though epilepsy is treatable and, once treated, does not result in impaired

functioning for many, within the dominant disability perspective, it is still seen as a disabling condition. In this research, epilepsy was acknowledged as a disabling, biopsychosocial condition. Socially, epilepsy results in stigma, discrimination, and exclusion; medically it could impair cognitive functioning, intellectual capacity, and physical ability; and psychologically it might lead to depression and anxiety (WHO, 2016). This biopsychosocial view aligns with the WHO's (2011) definition (and social model) of disability. While acknowledging that epilepsy is a disability, Calvert (2011) pointed to the complex relationship between epilepsy and disability, with each resulting in the other. For example, some people with epilepsy have a physical disability while some people with a physical disability have epilepsy, argued Calvert (2011). Similarly, ESA (2014) argued that epilepsy fits the definition of disability provided for in the Employment Equity Act (Government of South Africa, 1998) and the International Classification of Functioning, Disability and Health (ICF) in terms of impairment and barriers to equal participation, as shown in Figure 2.1. In Zimbabwe, the ESF is registered as a disability organisation and some people with epilepsy, disabled by the condition, qualify for government disability payments. Most epilepsy associations in Africa form part of the region's disability movement, even though not all people with epilepsy are necessarily disabled. For some, seizure control enables them to live full and satisfying lives. Perhaps the intermittent nature of epilepsy, also make it difficult for society and people with epilepsy to recognise it as a disability.

As shown in Figure 2.1, epilepsy is a health condition that could result in both functioning and participation restrictions. Once medicated, and body (i.e. brain) functions are restored, participation is increased or restored. It is society's response to epilepsy – and its failure to accommodate people with epilepsy in workplaces, schools, and public and private spaces – that renders it a disability, as well as government failure to provide essential medical resources. Resultantly, more people with epilepsy become disabled, especially in the Global South (Baskind & Birbeck, 2005a, 2005b; Meinardi et al., 2001). In 2010, epilepsy contributed

to over 17 million disability-adjusted life years and ranked 20th on the list of causes for years lived with disability (Vos, Flaxman et al., 2012).

**Figure 2.1: ICF use with epilepsy**

HEALTH CONDITION
(disrder or condition)
EPILEPSY

BODY FUNCTIONS & STRUCTURES
Problems of brain, sensory or body functions

ACTIVITIES
Recurring difficulty with physical activities and intellectual ability

PARTICIPATION
Restricted social interaction, education, training or employment

ENVIRONMENTAL FACTORS
Stigma
Health services
Social support
Policies

PERSONAL FACTORS
Age
Type of seizures
Gender
Education

Adapted from ICF diagram (WHO, 2001)

*Social model*

The social model of disability arose to address the shortcomings of the traditional and medical models by emphasising society's role in advancing human rights, equality of opportunity, nondiscrimination, skills development, employment access, and social protection for persons with disabilities. The social model of disability emerged from the ideas and principles of the Union of the Physically Impaired Against Segregation (UPIAS), an early disability rights

organisation in the United Kingdom which promoted the idea that disability was more than an individual or personal issue (Oliver, 1990, 2009, 2013). It required social and political measures to ensure people with disabilities enjoyed the same opportunities as those in the general population (Morgan, 2012; Oliver, 2013). The Disabled Peoples Movement (DPM) promoted the social model of disability and a service-user perspective (Oliver, 2013). The social model highlighted the structural barriers and social inequalities endured by disabled people, who were among the poorest, most excluded, and devalued in society (Mtetwa, 2011, 2016; Oliver, 2013). It drew attention to stigma and discrimination caused by alienating or non-inclusive social structures, policies, processes, and practices (Morgan, 2012; Oliver, 2009).

## *Human rights model*

The human rights model contended that prior models focused on needs and deficits rather than entitlements and rights. The CRPD (UN, 2006a) recognised disabled people's right to be treated with dignity and respect (Eide, 2012; Murungi, Mandlate, & Armah, 2013). Though they experienced life differently due to their disability, they were people (rather than disability) first and were entitled to the rights enjoyed by others in society (UN, 2006a). The human rights model gave rise to an empowering approach, in which people participated in decisions about their lives. It championed the enforceability of rights and called for social action and justice (Mgonela, 2010; Mtetwa, 2016; Murimi, 2013). Banks and Polack, (2015) argued that rights and justice were intertwined. Fulfilment of rights meant enabling people to exercise choice, participate in society as peers, and access its opportunities and benefits (Fraser, 2008). It meant targeted programs and mainstreaming disability for people to reach their full potential (Banks & Polack, 2015; Mgonela, 2010; Mtetwa, 2016; Murimi, 2013; Peta, McKenzie, & Kathard, 2015; UN, 2006). The CRPD is a key pillar of the human rights approach because it mainstreamed disability in international development (Kett, Lang, & Trani, 2009; Visagie, Scheffler, & Schneider, 2013). However, Lang (2009) warned that the policy 'was not a

sufficient instrument for the enforcement of disability rights and should not be perceived as a panacea that will end disability discrimination' (p. 1). Citing examples from Zimbabwe and Nigeria, Lang (2009) showed that local laws were difficult to change and politicians and the disability movement had conflicting goals.

*Affirmation model*

The affirmative model is a non-tragic view of disability that sees conditions like epilepsy as part of human diversity. The model helps people with disability to take a positive view of their condition and helps society to see disability from the perpective of people with the condition. Its proponents contended that every human was impaired in some way though the degree of disability emanating from the impairment varied greatly (Lang, 2001; Swain & French, 2000). They called for people experiencing disability to celebrate and take pride in their unique identity and life-enriching attributes (McCormack & Collins, 2012). It was an extension of the social model of disability (Swain & French, 2000). However, the model has been criticised for neglecting the differences between disabled and able-bodied people. This could weaken the disability movement, especially if people with disabilities did not identify with the movement (Lang, 2001).

*Economic model*

Employment would help people with epilepsy acquire treatment services that they require. In the absence of employment, support from their governments would be expected to assist them. Given the low cost of epilepsy management, even resource-poor countries could provide free or affordable treatment for people with epilepsy (Chisholm, 2005; Megiddo et al., 2016). The WHO (2016) estimated that the cost of epilepsy treatment could be as low as USD5 per person per year. Megiddo et al. (2016) reported that 'expanding and publicly financing epilepsy treatment in India averts substantial disease burden' (p. 464). However, unemployment and the

failure of most countries in the Global South to provide even the most basic first-line treatment resulted in significant economic and social impacts for people with epilepsy, their families, communities, and nations.

Employment and income perspectives are limited in epilepsy management, as in disability in general. However, Epilepsy South Africa (ESA, 2014) runs economic empowerment programs, including sheltered workshops, and a mainstream employment program named Epilepsy Disability Employment Support Services (eDESS). Sheltered workshops in Cape Town employ people with epilepsy in a factory that makes furniture for local and foreign markets and another producing mats and baskets. The eDESS links people with epilepsy, ESA, and employers. Its major focus is employment preparation, to facilitate workplace adjustment and legal compliance, and supportive employment services, including skills development, short-term employment, induction, and mentoring (ESA, 2014). The Employment Equity Act (Government of South Africa (1998) promotes affirmative action, education and vocational training, and sensitisation of employers to foster positive attitudes towards people with epilepsy. Though the ESF in Zimbabwe does not run sheltered workshops, it promotes small self-help projects for its members and employer sensitisation initiatives. Self-help projects have been supported by the IBE (2016) in countries like Zambia, Kenya, Cameroon, and Uganda.

## Management of epilepsy in Zimbabwe

In Zimbabwe, the management of epilepsy falls under the Mental Health Unit in the Ministry of Health and Child Welfare. Medical and healthcare practice is regulated by the 6th Essential Medicines List and Standard Treatment Guidelines for Zimbabwe, commonly referred to as the Essential Drugs List for Zimbabwe (EDLIZ) (Ministry of Health and Child Welfare, 2011). The guidelines authorise health workers, mostly medical/psychiatric practitioners and nurses,

to diagnose and treat epilepsy and provides training standards for them. The Ministry follows a public health approach (WHO, 1978) with services delivered at three levels:

1. Primary healthcare is the first level of contact individuals, families, and communities have with the healthcare system.
2. Secondary healthcare is offered by a specialist practitioner or medical facility upon referral by a primary – community-based – care provider.
3. Tertiary healthcare is provided by specialists working in a centre that has dedicated personnel and facilities for special investigation and treatment, usually on referral from primary or secondary medical care personnel.

Primary healthcare facilities were usually within walking distance of most communities, that is, 10 kilometres or more (Choruma, 2007; Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF), 2003). Sebit and Mielke (2005) reported that the five major referral hospitals, all of which are in urban areas, offered limited services for people with epilepsy, while private health facilities in urban areas were beyond the reach of most Zimbabweans. There was a shortage of anti-epileptic medicines and, often, people with epilepsy could not afford the cost of travel, medicines, tests, and hospital fees. Mielke et al. (2000) reported increasing concern that 'patient-related concerns were not being addressed. These include important social and psychological issues, such as advice for employers and employees, advocacy at the work-place and daily functioning issues for more severely disabled PWE' (p. 260).

The ESF – the main nongovernment organisation dedicated to supporting people with epilepsy in Zimbabwe – attempted to address these issues. It was formed in 1990 by Nicholas George, a person with epilepsy, with the support of parents of children with epilepsy and professionals, notably Professor Laurence Levy, the first neurosurgeon in Zimbabwe (Devlieger et al., 1994; ESF, 1992, 2012). The ESF has a social rehabilitation unit and a clinic

with an EEG. Its Nicholas George Centre for the treatment of epilepsy also provides advocacy services and administrative support for income-generating projects, and works to influence policy change (ESF, 2012). Its rehabilitation centre offers health education, disagnosis, treatment, dispensary counselling, and limited psychosocial and economic interventions. Health education programs include awareness-raising events during National Epilepsy Awareness Week, International Epilepsy Day, and Purple Day. ESF also runs support groups in some areas of the country and its personnel included people with epilepsy.

As with most health voluntary organisations in Zimbabwe, the Ministry of Health and Child Welfare subsidises the salaries of health and allied health staff and the Department of Social Service sometimes provides minimal administrative support. The Zimbabwe League Against Epilepsy (ZLAE) is the only other NGO 'promoting epilepsy awareness, treatment and providing back up support to people with epilepsy' (Mugumbate & Nyanguru, 2013, p. 29).

## Conclusion

Inaccurate beliefs about, and lack of access to medical treatment for, epilepsy makes it disabling for most people with the condition in Zimbabwe. Surprisingly, once diagnosed, epilepsy is usually treatable and need not be a disability. In Zimbabwe, its social impact might be extremely debilitating due to entrenched stigma that requires social management. It is in the social management of epilepsy that social work can play an important role. This chapter discussed causes, symptoms, and prevalence, and perspectives of understanding and managing epilepsy. It highlighted the social aspects of epilepsy that makes it a disabling condition. The next chapter examines Nancy Fraser's theory of social justice undergirding this study and its usefulness for understanding the social injustices endured by people with epilepsy in Zimbabwe.

# CHAPTER 3

# Theoretical framework informing the study

This chapter discusses the theoretical framework informing this study. It begins with a discussion of Nancy Fraser's theory of social justice before a discussion of the nexus between social justice, social work, and disability. As already highlighted in Chapter 1, this study adopted Nancy Fraser's conception of social justice because of its attention to broader structural – economic, cultural/legal, and political – factors giving rise to injustice.

## Fraser's social justice theory

Feminist political philosopher and critical theorist, Nancy Fraser proposes a three-dimensional theory of social justice encompassing the economic, cultural/legal, and political domains (Fraser, Dahl, Stoltz, & Willig, 2004). Fraser views social injustice 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 bear the brunt of economic disadvantage, social stigma, and lack a political voice. Even though her work does not address disability directly, it analyses social harms generally (Danermark & Coniavitis, 2004). In her early theorising, Fraser was interested in the intersection between 'economic inequalities and culture and discourse' (Fraser et al., 2004, p. 375). Fraser 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] … 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; the unemployed; poor people; and people with disabilities. Economic and cultural 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, as a Marxist in the 1980s, she found herself drawing on Karl Marx and Max Weber to argue

> 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, Fraser argued for a third form of injustice, political subordination (Fraser, 2008, 2010). Neither redistribution nor recognition was adequate as a remedy for this kind of injustice, resulting in a third remedy, representation. Fraser's final argument was that these three remedies could potentially address injustice if disadvantaged people could participate in society as peers, making participation a key element of social justice. Each of these three forms of injustice, and participation, is discussed in turn.

## *Economic injustice*

Fraser argued consistently that economic injustice resulted from class-related exploitation, poverty, marginalisation, deprivation, and inequality (Fraser, 1995, 2001, 2008, 2010). Examples included unpaid labour, low pay, undesirable jobs, property ownership deprivation, and poor access to resources. Fraser (2008) borrowed these ideas from Karl Marx's theory of capitalist exploitation. Hence, Fraser believed the solution to this kind of injustice was economic restructuring that would include redistribution (e.g., income transfers),

reorganisation of the division of labour, and the transformation of economic structures (e.g., property ownership). Fraser (2008) termed these different remedies redistribution. Referring to the gender movement, Fraser said redistribution entailed challenging the *status quo* to foster equality for men and women (Fraser, 2000, 2004, 2008). However, Fraser realised that resource maldistribution was not the only form of injustice. Marginalised groups such as women were not only economically disadvantaged but were also subject to discrimination based on their status, which led to cultural injustice (Fraser, 2008).

## *Cultural injustice*

Cultural, symbolic or status injustice resulted from 'social patterns of representation, interpretation, and communication' (Fraser, 2008, p. 71). Fraser's idea of cultural injustice was influenced by Max Weber and Hegel (Fraser, 2000; Fraser et al., 2004). However, while Hegel focused on identity politics, Fraser et al. (2004) argued against it, calling for status politics. Status politics sought to change social structures and institutionalised patterns that perpetuated cultural injustice, as opposed to identity politics which sought the self-representation and recognition of denied identities without seeking to change the root causes of identity marginalisation (Fraser, 2000; Fraser et al., 2004). Fraser (2000) argued that identity politics tended to dislodge redistribution, instead of enhancing it. Examples of such patterns included cultural domination; unequal participation; disrespect of cultures; and invisibility of certain cultures. Movements for multiculturalism and international human rights attested the need for identity and status justice. Fraser (2008) argued that this axis of injustice was caused by status order and could not be achieved by redistribution but by a fight for recognition through seeking change in cultures and attitudes. Again, referring to gender, Fraser (2009) saw the fight for recognition being the fight for removing perceived social status differences between men and women, for example, invisible, unpaid care work and reproductive labour (Fraser, 2009). Fraser (2009) argued that women's problems were 'grounded in the deep structures of society' (p.

103). As a remedy, Fraser proposed revaluing disrespected identities, recognising cultural diversity (e.g., legal rights and protections) and the cultural symbols of marginalised people, and changing people's sense of self (Fraser, 2000, 2008). In short, Fraser called for transforming patterns of representation, interpretation, and communication and classified such remedies as recognition (Fraser, 2008, 2010).

Fraser's ideas on recognition blended, in some way, to those of Taylor (1994), Honneth (1997), and Morrison (2010). Morrison (2010) agreed that recognition could strengthen social inclusion. Fraser argued that justice required both recognition and redistribution but Taylor (1994) focused only on recognition. While Honneth (1997) acknowledged the role of redistribution, he, too, gave weight to recognition. Honneth focused on identity recognition, while Fraser emphasised status recognition. Fraser argued for recognition of people's standing as peers in social interaction and changing social institutions to deal with identity misrecognition that was characterised by public disapproval and undesirable virtues (Fraser, 2008). To deal with these elements of cultural injustice, Honneth called for respect for, and recognition or validation of, differences, and not only the distribution of material resources. Honneth (1997) saw recognition as involving, people recognised as individuals whose needs and desires were of unique value and whose capabilities were valuable to their community; being recognised as a person ascribed the same moral accountability to everyone, i.e., it led to universal equal treatment. Honneth called for a new understanding of social justice, arguing that Fraser had relegated and 'misrecognised' the most important axes of status subordination in society, namely, gender, race, disability, ethnicity, and religion. To Honneth (1997), status was more important than class and, rather than distribution, the remedy lay in revaluing disrespected identities and recognising difference.

The co-called Fraser-Honneth distribution-recognition debate led to the understanding that the struggle for recognition should be supplementing and enriching the struggle for

redistribution and not displacing it (Fraser, 2003; Fraser et al., 2004; Fraser & Honneth, 2003). Fraser acknowledged that both redistribution and recognition were important, later arguing they were 'two co-fundamental dimensions of justice which are mutually irreducible although practically intertwined' (Fraser et al., 2004, p. 376), while Honneth later acknowledged that the struggle for redistribution stemmed from the struggle for recognition (Honneth, 2001).

In the mid-1990s, Fraser began calling for an integrated conception of justice that would focus on addressing economic and cultural injustices, arguing for participation parity (discussed later), where misrecognised parties would be 'capable of participating on a par with the rest' (Fraser, 2000, p. 113). But she yet again saw another caveat harbouring social injustice, which could not be achieved by redistribution and recognition. This was a lack of voice or representation in the political domain.

## *Political injustice*

Fraser et al. (2004) argued that political subordination emanated from 'misframing', when 'governance structures and decision-making procedures' (p. 380) in, for example, patriarchal systems, global corporations, authoritarian states, and international policies failed to accurately represent the needs and claims of marginalised groups. They did this by failing to create formal (legal) processes for them to articulate their needs and challenge oppression, that is, by failing to give them a voice (Fraser, 2008; Fraser et al., 2004). Hence political injustice arose when there were no formal representative structures for people to exercise their rights. With globalisation and the migration of people, justice could no longer be confined to nation states, but cut across borders (Fraser, 2008; Fraser et al., 2004). It could only be removed by transforming or improving governance structures and decision-making procedures to give people representation through international human rights protocols and by participation (McNay, 2008). Fraser argued that the frame of social justice had expanded beyond nations due to globalisation and international migration (Fraser 2008). However, this trend was often

neglected in programs to achieve justice and resulted in misframing which, in turn, led to the subordination of the most pressing needs of marginalised groups in society, such as refugees, creating the need for nations to embrace justice frameworks promoted by international organisations, such the UN (Hölscher, 2014). In South Africa, Hölscher (2014) confirmed the central role of Fraser's concept of misframing in her research on social justice and refugees.

## *Parity of participation: Connecting the three axes of social justice*

Fraser's theory of social justice maintained that, for social justice to occur, economic (maldistribution), cultural (misrecognition), and political (misrepresentation) factors must all be addressed. Fraser argued that to remedy injustice, marginalised groups had to participate as peers economically, culturally, and politically. This brought a core dimension of Fraser's theory that cuts across all three forms of justice and their remedies, all of which were central to the claims of people with disability, namely, parity of participation. It is to this the discussion now turns.

Fraser argued that social justice did not require group recognition but recognition of the status of individuals making up a group or of the group itself relative to other groups (Fraser, 2001). Taken in the context of disability, this meant recognising individuals not only as unique actors who were being denied the opportunity to participate as equals in society, but also groups of people being stigmatised because of their differences. Fraser (2001) argued for 'parity of participation' which allowed 'all (adult) members of society to interact with one another as peers' (p. 6). This meant participation in economic (redistribution), cultural (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 marginalised individuals and groups from participating as peers (Danermark & Coniavitis, 2004).

While participation binds the three axes and makes Fraser's ideas more practical, critics of Fraser's theory of social justice, such as Honneth, have not been happy with her ideas on recognition. As already mentioned, Honneth (1997) initially argued that Fraser's theory did not fully recognise the most important axes of status subordination in society, namely, gender, race, disability, ethnicity, and religion. However, these were all later addressed.

Fraser's three axes were intertwined, creating a vicious circle of injustice though, at times, presented competing solutions (Fraser, 2008). For example, recognition called for some groups to be 'recognised' as groups, yet distribution called for the removal of such differentiation. To illustrate, the women's movement called for the abolition of divisions of labour to make men and women equal, as well as recognition of differences between the sexes (Fraser 2008). Fraser (2008) termed this the redistribution-recognition dilemma, which lay in whether to reinforce or transform societal structures that perpetuated injustice. The call for multicultural societies was an example of the attempt to dilute differences, while indigenisation and decolonisation sought to reclaim cultural heritages lost during colonisation (Fraser, 2008). In spite of these shortcomings, Hölscher (2014) showed that Fraser's theory 'looks set to enrich social work's commitment to social justice both in normative and practical terms' (p. 20). As shown in the next section, Fraser's theory provides a rich understanding of misframing and disability injustice.

**Nexus between social justice, social work practice, and disability**

As shown in preceding sections, none of the models of disability and perspectives fully accounted for the experience of people with disabilities and people with epilepsy. Nancy Fraser's theory of social justice offers a framework for disability justice (Hölscher, 2014). The disability rights movement has fought consistently for redistribution, recognition, and representation and the participation of people with disabilities in economic, cultural, and political life (Mladenov, 2016; Wasserman, Asch, Blustein, & Putnam, 2015). People with disabilities have long been treated as inferior and denied access to education, work skills, jobs, and favourable work environments (Mladenov, 2016). Some were unable to enter workplaces, because employers and employees thought them incompetent and undermined their progress (Knight, 2015). Some were denied treatment or other supports. Some had been labelled unstable, contagious, or demonic, labels that stigmatised and marginalised them (Oliver, 2013). Some had been segregated from society in institutions. Most lacked a voice, independence, and equal participation (Mtetwa, 2011, 2016). In terms of Fraser's social justice framework, the disability movement sought to end misrecognition, maldistribution, misrepresentation, and unequal participation (Mladenov, 2016; Wasserman et al., 2015).

*Social work approaches*

International Federation of Social Workers (IFSW) (2012) contended that social work should involve people with disability, their families, and communities through direct practice, groupwork, community development, policy practice, research, and advocacy. IFSW supports the participation of people with disabilities in the management of their condition and their everyday lives. The social work role is guided by professional values relating to social justice (equality and fairness), respect for persons, and self-determination (IFSW, 2012). The IFSW Code of Ethics (IFSW, 2012) states that social workers value human rights, individual

potential, a nonjudgmental attitude, and confidentiality, and challenge discrimination and exclusion. Social workers working in disability worldwide provide direct services in institutions or the community, while some engage in policy, research, and development (Chitereka, 2010; Oliver, 2013). These roles are discussed in turn.

*Direct practice*

Direct practice roles played by social workers vary from country to country but include counselling, advocacy, and family support. In Zimbabwe, social workers provide counselling and practical support for people in residential care (Chitereka, 2010; Jelsma Mielke, Powell, De Weerdt, & De Cock, 2015). In addition to counselling, in other countries, social work roles in institutions include assessment, training, research, and referrals, as shown in Table 3.1 (Beaulaurier & Taylor, 2001; Dhemba, 2011).

**Table 3.1: Social work direct practice roles with people with disability**

| Role | Activities |
|------|-----------|
| Counselling | <ul><li>Conduct accurate assessments to identify needs, plan interventions, and link people with services and benefits.</li><li>Help people access direct funding, such as health insurance, pensions, and other benefits, where these are available.</li><li>Help people with disabilities plan for, and remain in, employment.</li><li>Refer people to appropriate resources or services.</li></ul> |
| Advocacy | <ul><li>Reduce barriers and create pathways for vocational training.</li><li>Improve access to primary, secondary, and tertiary education for people with epilepsy by promoting school enrolment.</li><li>Create access to healthcare.</li></ul> |
| Social and family support | <ul><li>Offer social and family support to manage the person with epilepsy. facilitate their social engagement, and help them develop goals.</li><li>Group work for psychosocial support.</li><li>Engage in activities to raise community awareness to reduce stigma and discrimination.</li></ul> |

In most countries, social workers work independently or as part of rehabilitation teams for people with disabilities that might include doctors, nurses, rehabilitation workers, advocators, counsellors, employment officers, welfare officers, and teachers (Chitereka, 2010). Through direct practice, social workers ensure people's optimal social functioning by addressing the challenges hindering them from performing their social, economic, or political roles in society. They do this by conducting accurate assessments to identify needs, planning interventions, and linking people with services and benefits, such as disability grants (Chitereka, 2010).

In Zimbabwe, social workers refer people to appropriate resources or services provided by government, nongovernment, private, or community-based organisations (Chitereka, 2010). Often, people with disabilities find it hard to navigate fragmented services, and face challenges in securing and completing vocational training, hence the need for advocacy (Mtetwa, 2016; Rutsate, 2009). Chitereka (2010) described how social workers in Lesotho facilitated vocational rehabilitation by assisting people with disabilities to make choices about courses, acquire assistive devices, and gain skills.

Groupwork, or working with groups, is one of the ways in which social workers help people improve their social functioning. Its importance lay in its therapeutic, educative, and social functions. It brings people together in groups, where they could share their experiences and speak freely in an accepting environment. In Zimbabwe, the ESF use groupwork to train parents on seizure management, first aid, dealing with negative community attitudes, and engage in income-generation ventures.

*Policy practice and research*

Through policy work, social workers promote human rights. The IFSW (2012) noted that social workers are directed and guided by the CRPD (UN, 2006a) in improving legislation, and developing and implementing just policies. They foster social inclusion, self-determination,

and freedom by highlighting inequalities and advocating for inclusive policies. Chitereka (2010) argued that policy work ensure effective social structures. Social workers advocate for the employment of people with disabilities in the public sector (Campbell, 2011). Labour-related advocacy include promoting reasonable accommodation, open labour market participation, and vocational and professional rehabilitation.

Research on disability is limited in Africa, especially Sub-Saharan Africa, especially on prevalence, challenges, and opportunities (ILO, 2008). This renders people with disabilities invisible and forgotten (ILO, 2008). Gray, Plath, and Webb (2009) contend that social work practice should be informed by research, a view shared by the IFSW (2012) and IASW (2010). Research focused on issues surrounding disability, including opportunities, barriers, new technologies, and inclusion strategies and the employment experiences of people with disability (Campbell, 2011). Social workers carry out research to inform practice and contribute to the development of innovative, relevant, and appropriate services (Chitereka, 2010). Their overall aim is to better understand disability and develop more effective approaches in reducing its impact. In African countries, like Zimbabwe, there is a need to keep abreast of new trends in disability work and to determine the applicability of strategies and interventions to local contexts. Jelsma et al. (2015) conceded that there had been very little research on disability intervention.

*Developmental practice*

African countries have seen a shift towards developmental social work, which is viewed as empowering for indigenous people (Mupedziswa, 2001; Mupedziswa & Kubanga, 2016). Developmental social work sought culturally, socially, and economically appropriate approaches (Gray & Ariong, 2017). It addressed unjust structural disadvantages (Hall, 1990; Mupedziswa & Kubanga, 2016) and sought preventive solutions (Mupedziswa & Sinkamba,

2014) and increased income for the poor (Mhiribidi, 2010). Table 3.2 outlines the goals of developmental social work that seeks change at the individual, community, and national levels.

**Table 3.2: Developmental social work goals**

| Level | Strategy |
|---|---|
| Individual | Enhance human capital, i.e., individual knowledge and skills through education and training. |
| | Make employment accessible, i.e., create jobs. |
| | Initiate sustainable micro-enterprises, i.e., family and community owned businesses. |
| Community | Enhance community participation in development. |
| | Enhance access to, and use of, community services. |
| National | Develop policies to address structural inequality and socioeconomic disadvantage, such as employment creation. |
| | Ensure sustainable development for long-term change. |
| | Develop accessible markets for goods and services. |
| | Ensure planned multi-sectoral programs. |
| | Make social security viable. |

At the individual level, it seeks to build human capital through education and training, employment, and micro-enterprise development. At the community level, it seeks to enhance participation and give people a voice in development and increase access to services. At the national level, it seeks policies to address structural inequality by developing accessible markets for goods and services through multisectoral programs, including sustainable social security. In these ways, developmental social work aims to remove structural barriers to development.

Within developmental social work, community development involves raising awareness and mobilising resources to enhance employment opportunities (Chitereka, 2010; Jelsma et al., 2015). In economies like Zimbabwe, where opportunities for formal employment is limited, social workers engage in projects to provide opportunities for self-employment,

entrepreneurship, cooperative engagement, and business ownership (Mpofu & Harley, 2002; Mugumbate et al., 2017).

Social workers play an important role in coordinating disability programs, linking people with schools, churches, community leaders, and civil society organisations (Mugumbate et al., 2017). They provide information, share experiences, and offer training services, create partnerships with service users, providers, and the community based on the belief that people with disabilities would be more socially and economically productive if community transport, housing, education, and health services were more accessible (IASW, 2010; Oliver, 2013).

Gray (2010) highlighted that these developmental goals sustained the *status quo* within neoliberal welfare systems. Nevertheless, developmental social work implies a service continuum, starting with building human capital through the creation of a supportive family and community environment, and instituting policies and programs to ensure that people with disabilities have access to the social goods and services they need to lead full and productive lives, i.e., food, health, education, work, shelter, physical security, and participation. Developmental social work advocated an integrated approach including people with disabilities in mainstream service provision, education, and employment or economic participation and hence makes the community an important locus for disability programs. Social workers work with communities to take responsibility for their development through empowering programs that help people to manage their own lives and remain independent (Gray, 2010; Mupedziswa & Kubanga, 2016). Communities are reservoirs of social capital with social workers harnessing and building on individual and group strengths for targeted intervention programs. Ultimately, the aim of developmental social work and disability work is social justice.

### *Social justice and disability: a summary*

Table 3.3 shows the social work role in disability work discussed above, within Fraser's framework of social justice. It shows that redistribution, recognition, and representation were

essential to allow people with disabilities to interact or participate in society as peers. As Fraser (2001, 2008) argued, participation would allow people with disability to participate in all spheres of life and ultimately foster social justice. This is in line with the goals of social work of achieving a just society. It also shows strategies and methods that would allow people with disability to achieve social justice in society. While this is presented from a social work perspective, social workers are not the only professionals working to achieve social justice. Other stakeholders making a contribution include people with disability, disability advocates, carers, health and rehabilitation workers, educators, and legal professionals.

**Table 3.3: Social justice in disability work**

| Aspect of social justice | What would allow people with disabilities to participate as peers? |
|---|---|
| Redistribution | Provision of assistive devices and support with medical rehabilitation.<br>Caregiver support.<br>Supported basic and tertiary education.<br>Supported formal employment.<br>Funding for disability research. |
| Recognition | Restructuring workforce to ensure there is room for people with disabilities to join.<br>Participation of people with disabilities in crafting policies (giving a voice).<br>Acknowledge present and historical disadvantages faced by people with disability.<br>Recognise the need to plan buildings with people with disabilities in mind.<br>Recognition of the dignity and worthy of people with disabilities.<br>Recognition as people who can be economically productive as employees or business people. |
| Representation | Right to hold political office.<br>Own voices listened to.<br>Room for formal justice and recourse to justice.<br>Consultation during national budgets.<br>Formal associations/organisations represent the rights of people with disabilities. |

## Conclusion

This chapter drew on Fraser's theory of social justice to explain the situation of people with disabilities. It pointed to strategies to foster social justice that cohered with the objectives of social work and thinking in the field of disability. Nancy Fraser's theory offers an alternative that converges well with the purpose of social work. In Nancy Fraser's theory, people with disabling conditions, such as epilepsy, face social injustice and there is a need for recognition, representation, and resource redistribution to address their challenges. These challenges are not peculiar to Zimbabwe and, to address them, social workers worldwide play a role through direct services in institutions or the community while some do policy, research and development work. In this way, they endeavour to improve employment opportunities for people with disabilities, the focus of this thesis. The next chapter reviews literature on disability, epilepsy, and employment.

# CHAPTER 4

# Employment of people with disabilities

This chapter presents the results of a review of literature on the employment of people with disability and people with epilepsy. It describes the search methodology used and presents the results under three main headings:

1. Disability and employment globally.

2. Disability and employment in Zimbabwe.

3. Epilepsy and employment globally.

4. Epilepsy and employment in Africa and Zimbabwe.

## Literature search methodology

The main database used for the literature search was EBSCO. Most journals on disability and social work were included in the EBSCO database available in University of Newcastle (UON) electronic resources library. EBSCO contained more than 50 multidisciplinary databases, including the Social Science Citation Index, SocINDEX, Health Source, MEDLINE, Business Source Complete and Humanities International Complete. However, the Africa-Wide Information (AWI) database, presumably the largest database for African research was not available in EBSCO or in any of the UON's electronic resources. AWI was produced by National Inquiry Services Centre (NISC) in South Africa. AWI was subscription based so it was not accessible to the researcher. The search in EBSCO produced very few articles focusing on Africa so the search was extended to Google Scholar and African Journals Online (AJOL), an African database which was selected because it was the largest online database for African scholarly literature that was available in AWI and was open access.

A Boolean search approach was used. The main returns in this literature search were found in the journals relating to vocational rehabilitation and disability studies; health; social policy and social work; and psychology and mental health. The search was limited to peer-reviewed academic journal articles published after 2000, except for the scarce literature on Africa and Zimbabwe, which had no year limit. The main literature search was done in 2014 but was continuously updated as new literature was found. The literature on epilepsy in Africa was updated after the researcher attended the 3rd African Epilepsy Congress (AEC) held in Senegal in May 2017, where several researchers presented their work. After searching, computer-generated articles were screened manually based on topic and abstract.

As shown in Figure 4.1, for literature on disability and employment, the search terms used were 'disability (disabilities, disabled, handicap, or impairment) AND employment (or work, jobs, and economic)' which produced a total of 88,004 articles in EBSCO. The researcher used Google Scholar search which produced 844 articles. The ILO and AJOL search produced 683 articles. The searches from the three databases produced 89,300 articles. After full screening, 54 articles remained with nine focusing on Zimbabwe and 45 on the rest of the world, including Africa.

For literature on epilepsy and employment, the search was expanded to include AEC abstracts. The search terms were 'epilepsy AND employment (or work, jobs and economic)', which produced a total of 5,749, 139, 73, and 42 in EBSCO, AJOL, Google Scholar, and AEC respectively, as shown in Figure 4.2. The search from Africa only produced two articles focusing directly on employment, so it was expanded to include those examining education, stigma, and health. These two articles were from Senegal and Benin, meaning there was none from Zimbabwe. In total, the search on 'epilepsy AND employment' produced 5,961 articles. After full screening, 64 articles were included in the review.

**Figure 4.1: Literature search diagram for 'disability AND employment'**
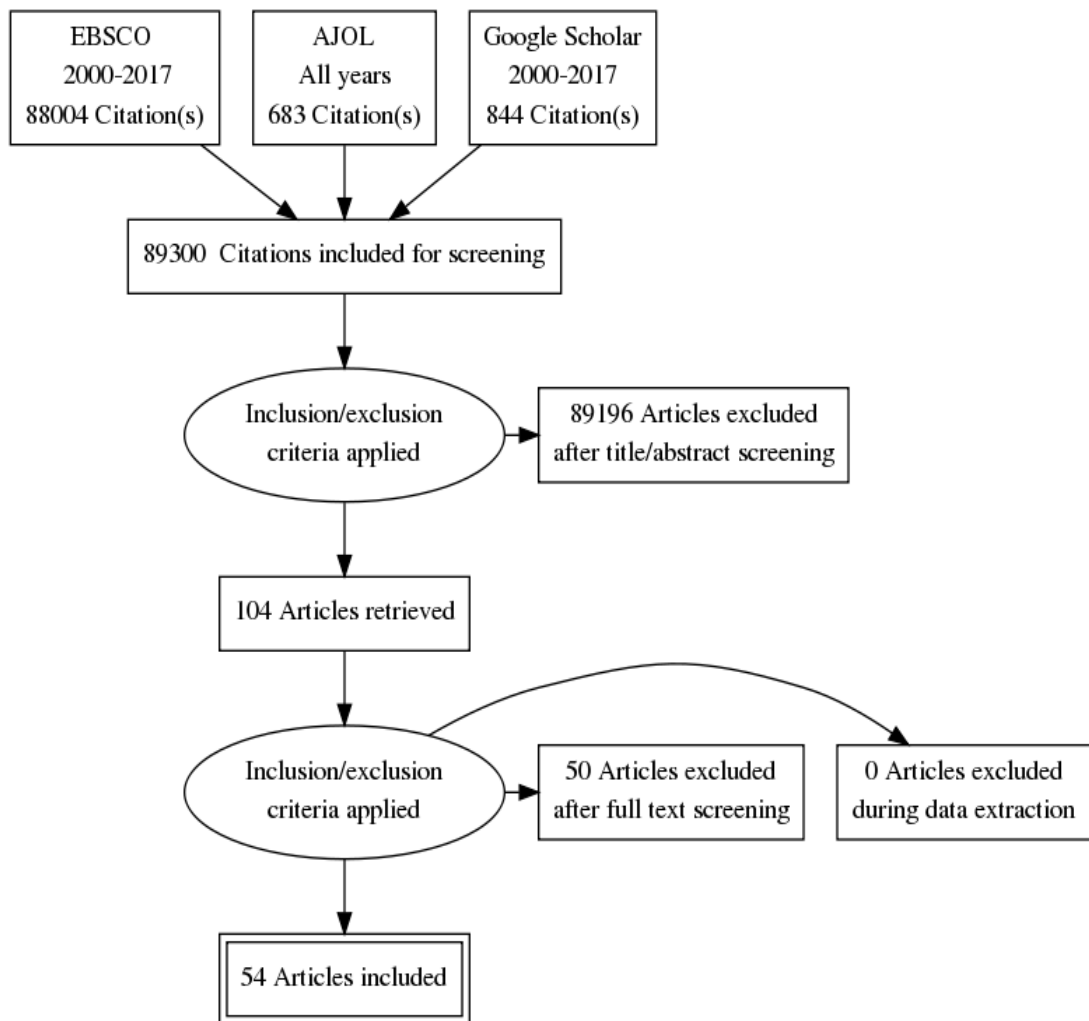


This PRISMA flow diagram was generated in open source dot program produced by Graphviz.

## Disability and employment globally

The main themes identified from the literature relating to disability were (i) employment exclusion; and (ii) barriers and facilitators to employment. These themes are presented in turn, supported by literature from both the Global South and North.

**Figure 4.2: Literature search diagram for 'epilepsy AND employment'**
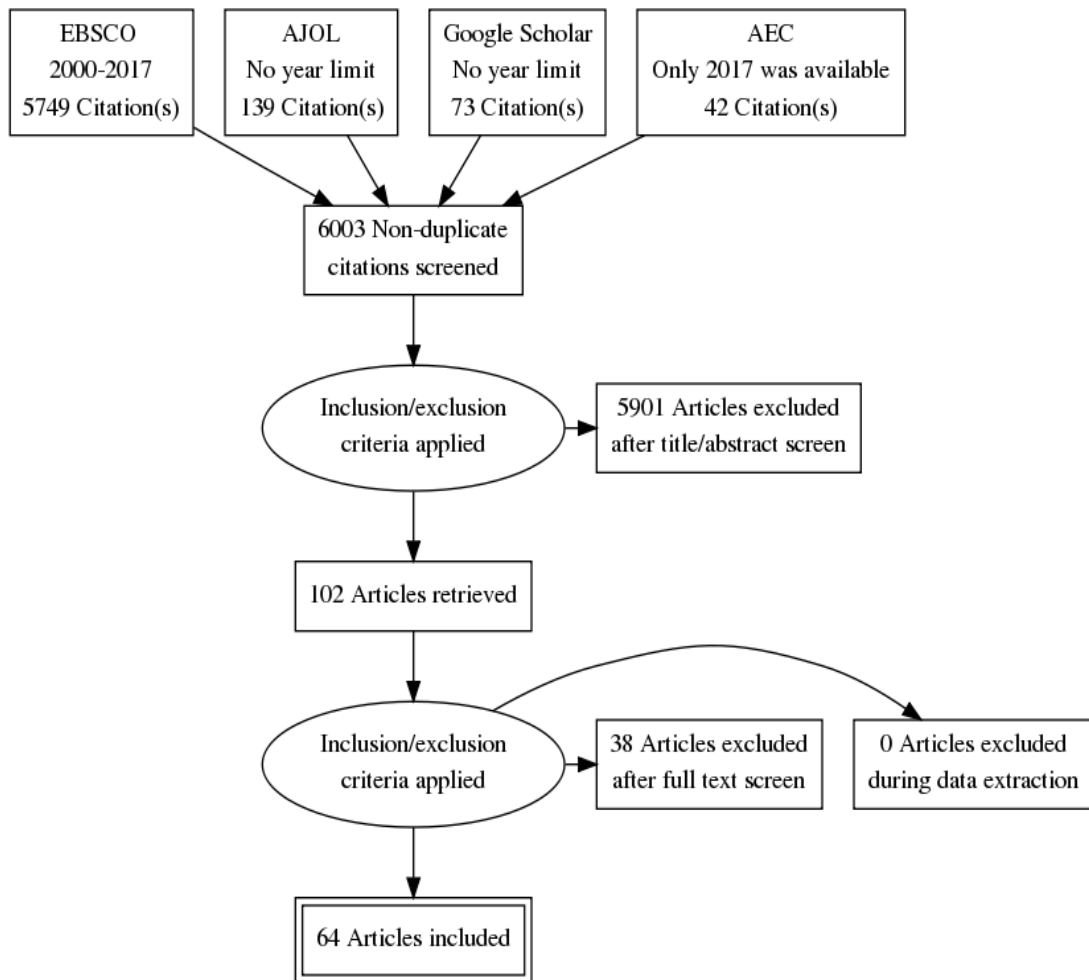


This PRISMA flow diagram was generated in open source dot program produced by Graphviz.

## *Employment exclusion of people with disabilities*

Studies on disability and employment pointed to discrimination against people with disabilities in both the Global North and South. In high-income countries of the Global North, people with disabilities had lower rates of employment. In Australia, for example, only 53% of people with disabilities were employed compared to 80% of nondisabled persons (ILO, 2008). In the European Union, 42% of people with disabilities were employed compared to 64% of nondisabled persons (ILO, 2008). In a United States of America (USA) study conducted in

2011, Erickson, von Schrader, Bruyère, and VanLooy (2014) found that the employment rate of working-age people with disabilities was 33.4% compared with 75.6% for people without disabilities. This 42.2% employment gap meant people with disabilities had a significantly lower household income and were far more likely to live in poverty than people without disabilities (Erickson et al. 2014). However, Rogan and Mank (2011) argued that employment rates for people with disabilities in the USA might be as low as 25%. Employee surveys confirmed that people with disabilities in the workplace faced pay and benefit disparities, diminished job security, and lower participation in organisational decision making. For example, Schur, Kruse, Blasi, and Blanck (2009) surveyed 30,000 employees from 14 companies in the USA and confirmed these disparities.

In the Global South, exclusion of people with disabilities was reported too. The World Bank (2004) reported that 80-90% of people with disabilities in South America and the Caribbean were unemployed or outside the workforce, while the majority of those employed received little or no monetary remuneration. In Argentina, during the same period, the World Bank (2004) estimated that the unemployment of people with disabilities was close to 91%. The Centre for International Rehabilitation (CIR) (2004) reported that only 25.1% of people with disabilities in Chile were employed compared to 51.6% in the general population. Mizunoya and Mitra (2013) used the World Health Survey data to review differences in employment rates between persons with and without disabilities in 15 developing countries. They found that people with disabilities had lower employment rates than those without disabilities in nine countries. Across countries, gaps in employment rates for people with disabilities were found more often for men than women, and the largest gap was found in people with multiple disabilities. Earlier, the ILO (2001) reported that 19% of disabled South Africans were employed compared to 35% of the whole population. Other studies in South Africa reinforced these studies. For example, Cramm, Nieboer, Finkenflügel, and Lorenzo

(2013) compared 523 young people with disabilities with their 466 nondisabled peers and concluded that the former were almost three times less likely to find employment than the latter. A similar study in the same country involving 120 young people with disabilities and their 117 nondisabled peers confirmed these findings a year later (Cramm, Lorenzo, & Nieboer, 2014).

Many have argued that the inclusion of people with disabilities in the labour market was contingent on a human rights focus (Maja et al., 2011; Marumoagae, 2012; Mitra, 2010; van Niekerk, 2008). In the absence of a human rights culture, 'cultural, social, physical and other barriers continue to prevent persons with disabilities in South Africa from enjoying their constitutional rights to equality, freedom and human dignity' (Marumoagae, 2012, p. 346). Hence, Visagie et al. (2013) argued that people with disabilities, like wheelchair users, often found it difficult to access employment facilities in South Africa.

Unemployment resulted in social and economic losses for individuals, families, communities, businesses, nations, and global corporations (Buckup, 2009). Losses included taxes and resources required by governments to run welfare systems and provide grants, food relief, and institutions for people with disabilities, found (Buckup, 2009). The estimated loss amounted to between 3 and 7% of GDP globally (Buckup, 2009). Economic losses were estimated at USD891 million, USD1.1 billion, and USD3.6 billion annually in Bangladesh, Morocco, and South Africa respectively (Banks & Polack, 2015). To address these losses, the ILO (2006) has worked to address the challenges faced by people with disabilities in employment:

In recent decades, the marginalization of many people with disabilities in society has been recognized as a human rights issue, resulting largely from barriers in the social and physical environment, rather than from the individual's inability to participate. This transition from a social welfare perspective to a rights-based approach, that is, to focus

on improving access to education and skills training, for example, is being reflected in legislation all over the world (p. 1).

The ILO (2007) recommended the mainstreaming of disability issues, the integration of services provided by public services, workplaces, and training institutions. In spite of efforts such as ILO's, literature shows various barriers and few facilitators to employment for people with disability as shown in the next section.

## Barriers and facilitators to employment for people with disabilities

The main barriers and facilitators found were: (i) employer attitudes; (ii) education and vocational training; (iii) access to social welfare and healthcare (iv) employment policies; (v) individual and psychosocial issues; and (viii) disability employment services. These are presented in turn.

### Employer attitudes

Research showed that negative employer attitudes were barriers while positive attitudes were facilitators to employment. The ILO (2007a) claimed that employer 'fears, myths and stereotypes come in all forms and are probably at the root cause of much discrimination and exclusion' (p. 3) in the workplace. This claim was supported by Lindsay et al.'s (2014) study of 19 employers' perceptions of young people with disabilities in Toronto (Canada) which addressed two questions: What did employers look for in young people they intended employing and did they see these attributes in people with disabilities? Lindsay et al. (2014) found that employers looked for a 'good fit' with the job, including technical knowledge, communication skills, work experience, and a well-prepared job application, along with 'soft skills' or relevant abilities and personality traits, such as, a positive attitude, dependability, and enthusiasm. However, young people with disabilities were perceived as neither possessing these desirable attributes nor the communication skills deemed necessary for the job. These

findings suggested that young people with disabilities were not valued in the workplace because they were perceived as lacking the skills for entry-level employment. Another study of USA employers (n=675) done by Erickson et al. (2014) reached similar conclusions, although negative attitudes and stereotypes, and the cost of training supervision, were lesser barriers compared to the perceived cost of accommodating people with disabilities in the workplace. The two studies cited are from Global North economies, but even in the Global South, negative attitudes exist. For example, an ILO (2004) study in Uganda found that people with disabilities were often perceived as unable to work. Their work potential was devalued and this limited their access to economic opportunities.

Other studies have shown that employers are not always negative when it comes to employment of people with disabilities. For example, positive attitudes were reported by Ju, Roberts, and Zhang (2013) who conducted a systematic review of mainly USA quantitative studies (n=15) on employer perceptions between 1999 and 2012. Ju et al. (2013) concluded that, though employers generally expressed a positive attitude toward workers with disabilities, they nevertheless had reservations about hiring people with certain types of disabilities such as seizure disorder or schizophrenia. Positive past experiences with individuals with disabilities were associated with a willingness to hire and retain employees with disabilities. Overall, they identified fewer concerns than previous reviews, which led to the question of whether employer attitudes to employing people with disabilities had changed. Erickson et al.'s (2014) study of workplace policies and practices in the USA also found that fewer employers reported organisational barriers to hiring individuals with disabilities. Rogan and Mank (2011) noted that 'all who are engaged in employment related services and supports must believe that people with disabilities, including those with high support needs, can work' (p. 186). Further, Wiggett-Barnard and Swartz (2012) argued that people with disabilities were committed to work and

were less likely to change employers as often as other workers. This commitment was important for productivity.

Positive attitudes were also reported in countries in the Global South. In Africa, for example, an ILO (2004) study in Uganda found that some employers were willing to hire people with disabilities or keep them at work. What these employers lacked was motivation, encouragement, and technical assistance. Further, Wiggett-Barnard and Swartz's (2012) study of employers (n=86) in South Africa concluded that human resource officers played a key role in the recruitment of people with disabilities. Companies that had appointed people with disabilities in the past were more willing to appoint them in the future. They most valued information on accommodation, like preparation of the environment and cost, and the impact of disability on job performance. The use of specialist recruitment agencies, the development of targeted recruitment plans, and staff sensitisation training and internships were found to be the best facilitators for the employment of people with disabilities.

*Education and vocational training*

Several studies found a lack of access to education was a major barrier to economic participation for people with disabilities (Abidi & Sharma, 2014; Banks & Polack, 2015; Échevin, 2013; Liao & Zhao, 2013; Schur, 2009; Wolffe et al., 2013a). Abidi and Sharma (2014) studied more than 300 top universities and colleges in India and concluded that low employment rates were linked to a lack of education and vocational training for people with disabilities. The average rate of students with disabilities in tertiary education had remained below one percent, reported Abidi and Sharma (2014). Further, their research found that a lack of employment qualifications was a major barrier in India, making it harder to meet the three percent quota in public sector jobs for people with physical, visual, and hearing impairments that was set by the government. Consequently, there was a huge backlog with 6611 vacancies across 65 government ministries and departments, which was partly attributed to poor

educational and vocational training opportunities for people with disabilities. Similar findings were reported in China by Liao and Zhao (2013) who found that each year of schooling led to wage increases of between 5-8% for people with disabilities while low education corresponded with low salaries. Studies in Africa also showed that education and training of people with disabilities improved their opportunities. For example, in Cape Verde, Échevin (2013) assessed the employment and school enrolment gaps between disabled and nondisabled persons, using the 2000 Cape Verdean census. Échevin (2013) concluded that people with disabilities were disadvantaged in the labour market by a lack of educational opportunities. In terms of educational enrolment, 88.4% of nondisabled persons were literate as compared to 72.5% of persons with disabilities. Likewise, a qualitative study among people with visual impairments in Nigeria found most respondents reported that further education was the key to improving their work situations (Wolffe et al., 2013b). Wolffe et al.'s (2013b) quantitative analysis in the same study showed an association between level of education and earnings, and level of education and confidence, indicating the need for post-secondary school support.

In the Global North, education and training too has been reported as a facilitator of employment for people with disability. This is illustrated in Schur et al.'s (2009) study on workplace disparities and corporate culture in the USA that concluded that people with disabilities received little formal and informal training, making them less attractive to employers. Schur et al. (2009) showed that people with disabilities lacked training opportunities in the workplace to advance their skills. Resultantly, they received lower average pay and less job security.

While studies reported so far focused on education as a barrier or facilitator, the ILO (2007, 2016) went further to detail the kind of skills that would improve employment opportunities for people with disabilities. The ILO (2007) reported that vocational training improved the competitiveness of people with disabilities and enabled them to find and maintain

work or to engage in business and informal income-generating activities. The ILO (2016) held that training must be flexible, accessible, and meet the individual needs of people with disabilities and that trainers should receive training in dealing with people with different forms of impairments. The ILO (2007) recommended a set of skills to improve employment outcomes of people with disabilities, as shown in Table 4.1.

**Table 4.1: Skills to improve employment opportunities**

| Category of skills | Examples of skills | Ways to acquire these skills |
|---|---|---|
| Personal | Grooming and motivation. | Socialisation and work trials. |
| Foundational or academic | Literacy and numeracy. | Basic, secondary, and informal education, and pre-vocational training. |
| Core or transferable skills | Communication skills, team skills, problem solving and decision-making skills, initiative and enterprise skills, planning and organising skills, self-management skills and learning skills. | Work trials and work experience placements where a jobseeker worked in a real job for a fixed trial period. Pre-employment training. |
| Technical skills | Carpentry, using a computer, tailoring, weaving, metal work and shoe making. | Mentoring/apprenticeship, where a more experienced employee or community member provided mentorship. Job coaching, where a student worked alongside a trained staff member. |
| Entrepreneurial and business management skills | Book keeping, risk assessment, market analysis, planning, goal setting, problem solving and how to obtain information. | Training in entrepreneurial and business skills. Continuous skills up-grading. |

Training programs that incorporated these skills were likely to produce competent and well-performing people with disabilities. A good mix of these skills and job knowledge produced competence, while a mix of skills, job knowledge, and attitudes produced performance. Industry could also establish enterprises with training and production elements, thus enabling jobseekers to develop a set of skills through work-based training: 'The

58

workplace, whether formal or informal, is the best place to learn and improve core skills for work' (ILO, 2007, p. 78). The ILO (2007) warned against designated jobs for people with disabilities believing that, with the right mix of skills development and support, they could fill most positions. It recommended training centres to employ experienced trainers aware of effective methodologies to teach people with disabilities, and enhanced access to physical facilities, and training materials and equipment. Further, training centres ought to provide job-search assistance, linkages with employers, and on-the-job training while training costs should be kept low by offering subsidies and scholarships to ensure access (ILO, 2007).

## *Access to social welfare and healthcare*

As already mentioned, education and training improved disability employment. Public educational and training services facilitated employment together with health, social welfare and employment services (ILO, 2007). However, social welfare and social development services were often minimal or non-existent, and there was a lack of access to welfare resources for assistive devices and technology; buildings were not designed to accommodate people with disabilities; and transport and training provision left much to be desired (ILO, 2008). While social welfare was viewed as a facilitator of employment by ILO (2007, 2008a), Sung, Muller, Jones, and Fong (2014) attributed the low number of people with disabilities in the labour market to the large number of people on disability support grants in South Africa. While labour force participation in the general population was 40% and 41% in 2002 and 2006, respectively, for people with disabilities, it fell from 18.4% to 12.3% during the same period. The number of people on disability grants rose from over 600,000 in 2000 to over 1.3 million in 2006. The grants paid totalled R4.6 billion (USD353 million) and R12.2b (USD937 million) in 2000 and 2006, respectively. Mitra (2008, 2010) highlighted other possible factors, including the inclusion of people with the Human Immunodeficiency Virus (HIV) and Acquired

Immunodeficiency Syndrome (AIDS) on disability grant payments and the changing nature of the South African job market.

Besides welfare services, healthcare services were cited as another factor that influenced employment of people with disabilities by Banks and Polack (2015). In their study on economic costs of excluding people with disabilities, they found that access to healthcare was a major barrier to economic participation for people with disabilities. Inaccessible health services resulted in people with disabilities failing to get timely health services and this, in turn, affected their economic participation. The costs of health services were high and unaffordable for most people with disabilities, while poor health decreased their productivity (Banks & Polack, 2015).

*Employment policies*

An ILO (2004) study in Uganda found a lack of adequate policies to deal comprehensively with people with disabilities in employment at the national and workplace levels. The ILO (2008) observed that most countries had outdated policies, based on welfare models that were inadequate for dealing with the complex needs of people with disabilities. Workplace policies were needed to create a receptive environment for the hiring and retention of employees with disabilities (Erickson et al., 2014). Similarly, Maja, Mann, Sing, Steyn, and Naidoo (2011) reported that, while South Africa had national and workplace policies (e.g., the Employment Equity Act 55 of 1998 and the National Disability Strategy White Paper of 1997) to promote work inclusion of people with disabilities, these were not being uniformly implemented. Other researchers reached the same conclusion in an assessment of South Africa's Public Service Department and national legislation relating to disability equity (Gathiram, 2007; Gida & Ortlepp, 2007; Schneider et al., 2016; van Staden, 2011; Visagie et al., 2013). Even in the South African private sector, the Code of Good Practice on the Employment of People with

Disabilities (CGPEPD) was not being fully implemented by companies in Johannesburg, who were founders of, and signatories to, this code (Jakovljevic & Buckley, 2011).

In the USA, Erickson et al. (2014) studied the policies and practices of companies via a survey of employers (n=675). Most organisations surveyed had diversity and inclusion plans. However, only a few organisation's policies were effective, argued Erickson et al. (2014). Those that had diversity and inclusion plans had a centralised accommodation fund, formalised decision-making processes for the case-by-case provision of accommodation, and a disability-focused network (employee resource and affinity group).

Given that many people with disabilities were left out of legislation, policies and services, the ILO (2005) called for partnerships between government, nongovernment, people with disabilities, and academic researchers to focus on human rights legislation and job creation and training. Legislation safeguarding the rights of people with disabilities often included quota systems, levies for employees who failed to comply with required quotas, hiring incentives, promotional schemes, technical support, and other measures (ILO, 2007). The ILO (2013) emphasised the importance of job availability and recommended that communities and disabled people's organisations (DPOs) should build strong links with employers because, without them, training and support would be ineffective (ILO, 2007).

*Individual and psychosocial issues*

Individual issues such as impairments and gender; and pyschosocial issues such as self-esteem have been found to influence employment. Soeker, Van Rensburg, and Travill (2012) investigated the return-to-work progress of individuals with mild to moderate brain injury (n=10) in South Africa and found that, following the brain injury, the participants experienced a loss of function, a fear of the future, and loss of confidence in their work roles. This was mitigated when workers actively engaged in rehabilitation and occupational routines were

adapted accordingly. Though their injury affected their work productivity, with social support, they developed the confidence needed to perform their duties.

Commonly held stereotypes about limited capacity for work of people with psychiatric disabilities were not justified in the case of many participants in a South African study that used life stories to refute the myth that people with psychiatric disabilities 'cannot function in the open labour market' (van Niekerk, 2010, p. 22). The study showed how work problems were erroneously ascribed to the psychiatric condition.

A study of 172 people with visual impairments in Nigeria found that workplace challenges related more to the environment than the disability, including out-of-date or inaccessible equipment and materials, inadequate assistance, transportation issues, poor remuneration, weak job status, workplace discrimination, lack of funds or time, inaccessible housing, and limited training opportunities (Wolffe et al., 2013a, 2013b). Further, in South Africa, Cramm et al. (2014) found that adequate attention to workers' health issues led to better work performance. An ILO study in Uganda found out that physical barriers resulted in people with disabilities failing to access buildings for work or for services thereby limiting their employment opportunities (ILO, 2004).

While employer perceptions were often negative based on impairments, the ILO (2007) argued that employing people with disabilities had several advantages. People with disability were as productive and reliable as any other employees; they had built transferable problem-solving skills through their experiences; they had better work attendance; they stayed longer with employers; and they had fewer accidents. Besides, disability on its own created a large market of commodities and consumers running into billions of dollars. Organisations employing people with disabilities were more accessible to the public and they increased their positive image by employing people with disabilities. Employers who employed a person with a disability were likely to employ other people with disabilities. The ILO (2007) cited the

example of the Dupont Corporation, which measured the performance of its employees with disability and concluded that they performed on par with, or better than, nondisabled staff regarding attendance, safety, and job performance despite their impairments.

The ILO (2007) reported that adult women and girls with disabilities were among the most disadvantaged groups due to their lack of access to education, employment, and public services. They were less likely to go into business and those that did were less likely to succeed than men. Employed women were often 'underemployed … earn less money, experience less job security and have fewer chances of advancement' (ILO, 2008, p. 1). Women with disabilities were less likely to find decent work, despite calls for equality of treatment for women and men with disabilities (ILO, 2015). Reasons for these disparities emanated from cultural and religious divisions of labour between men and women that were more pronounced in more patriachal countries of the Global South (ILO, 2008).

People with disabilities might have psychosocial issues resulting in low expectations and aspirations leading to low achievement (ILO, 2007). There were several reasons for this, including low societal and family expectations. Some societies expected people with disabilities to achieve very little (ILO (2007). The ILO (2007) cited examples of persons with disabilities, such as Joshua Malinga and Alexander Phiri from Zimbabwe, who were institutionalised and trained to be shoemakers, but aimed higher. Joshua became Mayor of Zimbabwe's second biggest city, Bulawayo, and a senator. Alexander became head of Southern Africa Federation of Disabled People (SAFOD). The ILO (2008) recommended that, instead of narrowly focusing on skills, the personal attributes of people with disabilities, their aspirations, motivation, creativity, critical thinking, friendliness, and self-confidence, should be developed during training. Low self-esteem resulted in a lack of motivation and doubts about performance and job readiness (ILO, 2015).

*Disability employment services*

With the right type and intensity of support, it was possible to integrate people with disabilities into competitive employment (Sing, 2012; van Niekerk, 2008). Van Niekerk's (2008) study in South Africa arrived at four basic requisites for supported employment: (i) sourcing of job opportunities; (ii) planning for disclosure; (iii) disability awareness of workers and co-workers; and (iv) practical assistance, including financial and non-financial support to supply people with disabilities with all the equipment needed to get to work on time and fulfil their duties. These basic requisites were supported by other researchers in South Africa like Jakovljevic and Buckley (2011) whose research found that technological support, such as special computer programs for people with visual impairment reduced physical barriers. However, these basic attributes for supported employment were jeopardised by a lack of resource provision by companies and government (Gida, & Ortlepp, 2007; van Staden, 2011; Wiggett-Barnard & Swartz, 2012). Additionally, in South Africa, as in many other countries, there was no legislation to buttress supported employment (van Niekerk et al., 2011), while Wiggett-Barnard and Swartz (2012) argued that supported employment was best offered by specialist recruitment agencies.

Other public services cited included credit facilities. Credit facilities − from banks, microfinance institutions, rotating savings clubs, and government − for people with disabilities were limited yet they were important to self-employment (ILO, 2007). People with disabilities often worked in the informal sector, running small businesses or engaging in other entrepreneurial activities (Lorenzo et al., 2007). Lorenzo et al. (2007) found that people with disabilities valued the independence the informal sector provided, as well as the dignity associated with having a small business. However, they lacked support to run viable self-help enterprises. Credit facilities were expensive and excluded people with disabilities. Donors

usually supported short-term projects for a limited number of people with disabilities (ILO, 2007).

Disability employment services were found to be a major component of vocational rehabilitation services, within rehabilitation services generally (Yuh, Yun-Tung, Meng-Hsiu, and Shih, 2013). The ILO (2005) recommended that employment services be adapted to the needs of people with disabilities and those of employers. In relation to quotas, the ILO (2005) believed these were not enough on their own. Also needed were incentives to employers and people with disabilities and comprehensive policies and, in relation to sheltered employment, the ILO (2005) recommended that these should not equate to isolated and underpaid jobs. The ILO (2007) argued for creative models like community-based contracts. Other employment services recommended by the ILO (2007) are presented in Table 4.2.

**Table 4.2: Services to improve employment for people with disability**

| Category | Services |
|---|---|
| Individual focused | Job-matching and job-seeking skills enhancement. |
| | Supporting people with disabilities to establish businesses (accessing capital and marketing). |
| Employer focused | Networking with employment service providers. |
| | Developing relationships with employers. Networking with DPOs. |
| | Networking with workers' organisations and creating employer forums, such as the Employers' Forum on Disability in the USA. |
| Stakeholder focused | Networking with government. |
| | Developing relationships with trainers. |
| | Bringing all stakeholders involved in employment together. |

The roles listed in Table 4.2 are often carried out by government agencies providing employment services. However, such agencies were rare in most countries of the Global South (ILO, 2007). In the absence of government services, private employment agencies usually filled the gap but again these are rarely available in most countries. Often, DPOs, self-help

organisations, and community based organisations provided disability employment services, albeit on a small scale (ILO, 2007). However, in countries where the service listed in Table 4:2 existed, public service providers, employers, workers with disabilities, employment agencies, and trainers that promoted employment for people with disabilities were not well coordinated in most countries, hence they failed to achieve disability inclusion (ILO, 2007). Most organisations and institutions lacked disability inclusion policies, strategies, and action plans (ILO, 2015). The ILO (2015) developed a Disability Inclusion Strategy and Action Plan to run from 2014 to 2017. It included anticipated results, baseline indicators, targets, indicative activities, and key partners. Table 4.3 presents possible best practices in disability and employment promoted by the ILO (2015) and other organisations to help in the planning of disability employment inclusion.

**Table 4.3: Best practice in disability employment**

| Participants | Best practice |
|---|---|
| Employers | Disability inclusive organisation internal practices, premises, proceedings, and publications. |
| | Timely and specific inclusion plans. |
| | Equality of opportunity. |
| Government | High-level commitment from leaders in governments and employers' senior management. |
| | Effective national legislation. |
| People with disability | Adequate representation through workers unions |
| All participants | Tripartite arrangements bringing together government, employers, and employees, as well as stakeholders from civil society organisations. |
| | Strengthened knowledge base, including evidence-based practice and practice-based research. |
| | Equal treatment for women and men with disabilities. |
| | Effective internal and external communication, for example, through websites, through the International day for Persons with Disabilities, or best practice guidelines. |

As shown in Table 4:3, best practice is achieved by employers, government and people with disability working together. While the best practice, and the literature discussed in this section, refers to disability including epilepsy in general, the next section deals with literature more specific epilepsy and employment.

## Disability and employment in Zimbabwe

Research on disability and employment in Zimbabwe shows barriers like attitudes, physical barriers and lack of education. A labour market participation survey done by the Zimbabwe Statistics Agency (ZSA) showed that more people with disabilities than those without were likely to be unemployed, due to sickness, retrenchment, or poor education (UNICEF, 2013). In the ZSA's analysis, even those who were not productively or decently employed, were considered employed, on the criteria already mentioned (Government of Zimbabwe, 2014). This contrasted with Zimbabwe's Constitution. Section 24:1 sought reasonable policies and measures 'to provide everyone with an opportunity to work in a freely chosen activity, in order to secure a decent living for themselves and their families' (Government of Zimbabwe, 2013, p. 23). The ILO (2016) stated that productive employment and decent work were important for sustainable development. Hence, this study considered productive and decent employment as key elements for achieving social justice for people with disabilities.

Research show availability of employment discrimination. A qualitative study into attitudes of employers showed that people with disability faced discrimination in the workplace (Mapuranga & Mutswanga, 2014). Workers with a disability were described as 'incompetent' because they constantly required assistance of co-workers. Employers said workers with disability 'scare off customers' and perceived job seekers with disability as lacking competence and qualifications. In terms of recommendations, Mapuranga & Mutswanga (2014) suggested

incentives like tax rebates to encourage employers to employ people with disabilities and implement existing anti-discrimination legislation.

Employers were sceptical of employing deaf people because of communication challenges and the fear that they will not be competent (Hlatywayo, Hlatywayo, & Mtezo, 2014). Some employers feared they would lose clients if they employed deaf employees. On a positive note, the study confirmed that some employers were more accommodating but complained that they did not have access to training to improve their communication with deaf employees. Hlatywayo et al. (2014) found that some employers were satisfied with the vocational competencies and performance of their deaf employees. The researchers recommended incentives for employers of people with disability and funding of self-help activities. While this study was not very comprehensive, it provided insights into the current situation of people with disability in Zimbabwe.

Environmental and social barriers were confirmed in a comprehensive survey on conditions of people with disability in Zimbabwe that was done in 2013 using a national representative sample of nearly 15 000 households drawn from all 10 provinces of the country (UNICEF, 2013). The research confirmed the environmental and social barriers reported in previous studies but, more importantly, found that:

1. Formal basic education among people with disabilities was lower (84.2%) than among people without disabilities (93.1%), although in all groups, males were more educated than females.

2. Fewer individuals with disabilities report that they are in formal, paid employment.

3. Fewer individuals with disabilities were tertiary students.

4. Six times more individuals with disability (14.8%) than without disability (2.2%) report that they are retired, sick or too old to work.

5. Lower general physical and mental health for people with disability.

UNICEF (2013) showed that people with disability were less involved in formal employment and higher education as compared to individuals without disability. The study showed that more people with disability had not been employed previously and across the two groups, women were more affected. Illness and disability were cited as main causes of unemployment among people with disability.

Lang and Charowa (2007) found that fragmented disability policies, inadequate social assistance grants, a lack of education and employment, and poor representation were barriers to employment. While there were policies in place, they were inadequate and thus not implemented. They recommended more effective policy provisions on social assistance, education, and employment. Also, since nongovernment organisations had not been strong enough to challenge the multiple institutional, attitudinal, and environmental barriers found in their study, Lang and Charowa (2007) suggested capacity building was needed to make these organisations more effective.

Marongwe and Mate (2007) argued that disability exclusion and marginalisation emanated from traditional Zimbabwean society that valued 'normal' children as an economic and social investment. As a result, people with disability had low human, social, physical, and financial capital. Human and social capital related to individual capacity and social networks respectively. Physical capital related to accessibility to buildings and other facilities. Financial capital related to access to finances required to run successful businesses and to buy assets. Mtetwa and Nyikahadzoi (2013) studied the socioeconomic circumstances of children with disabilities and concluded that they were 'unprofitable assets' in the family because they could not contribute to the household economy.

Choruma (2007) concluded that 'the root of unemployment is lack of education, lack of disability-friendly workplace environments, and lack of support for and understanding of

disability issues by employers and able-bodied colleagues' (p. 22). The SINTEF (2003) study on living conditions found that:

1. 29% of people with disability had never attended school compared to 10% nondisabled.

2. No difference between employment and pay rates between people with disability and these without although women with disability reported lower employment rates.

3.  31% were in informal jobs compared to 23% of nondisabled.

4. Only 12.3% received a government grant.

The study showed that services, like treatment, were expensive and inaccessible. A follow-up study in Malawi, Zambia, Mozambique, and other Southern African countries confirmed the dire situation of people with disabilities (Eide, 2012; SINTEF, 2003a, 2004, 2006, 2009). In the Zimbabwe study, the finding that there was no difference between employment levels was attributed to the work of institutions providing training to people with disability, such as Jairosi Jiri and Ruwa Rehabilitation centre. However, the study focused on people with activity limitations so might have excluded disabilities like epilepsy.

These studies on disability in Zimbabwe confirmed findings from other countries, where people with disabilities faced social, environmental, and social barriers to employment. Collectively, these studies provided insight into the barriers encountered by people with epilepsy. A closer examination of the international literature follows.

## Epilepsy and employment globally

A review of literature relating to epilepsy and employment outside Africa revealed several themes as follows: (i) individual predictors of employment outcomes; (ii) social barriers to

employment; and (iii) role of employment services. These themes are discussed in turn while literature from African studies was discussed in the subsequent section because it was few.

## *Individual predictors of employment outcomes*

Researchers have tried to understand individual factors associated with employment outcomes among people with epilepsy. A more recent research on predictors of employment among 146 people with epilepsy in Malaysia reported that high employability related to high self-esteem, high self-determined motivation, low self-perceived stigma and availability of social support (Wo, Lim, Choo, & Tan, 2016). Of the participants, 64.4% achieved high employability. Other factors that necessitated employability were education, type of epilepsy, ability to cope, lower family expectations and overprotection. People with generalised seizures were found to have better employment outcomes (Wo et al., 2016). The researchers proposed an employment model with three elements: (i) assessment of ability to work and provision of appropriate training, (ii) identifying positive factors in family and workplace, and (iii) cultivating self-determined motivation. An earlier systematic review by Wo et al. (2015) found that adjusted employment rate of people with uncontrolled seizures was comparable to those with controlled seizures. This result showed that factors that influenced employment were not only clinical but also social. While this study, and other discussed below provided insights into employment issues, they focused on demographic, clinical and psychological factors and not systemic factors (Wo et al., 2015).

A longitudinal study in Finland followed participants who were younger than 16 years until they reached 48 years of age (n=119) (Sillanpää & Schmidt, 2010). The study found that later onset of epilepsy in children of normal intelligence (i.e., occurring at the age of six years or older) was a reliable predictor of employment in early adulthood, especially with good vocational education. Normal intelligence, having offspring, uninterrupted remission, and no history of status epilepticus (a continuous seizure that is dangerous for a person with epilepsy)

appeared to predict lasting employment into midlife (Sillanpää & Schmidt, 2010). The three most significant factors were normal intelligence, age at diagnosis of epilepsy older than six years, and vocational education (at age 23 years). At 48 years, no history of status epilepticus and normal intelligence were the most significant factors. Even without intellectual handicap, Sillanpää and Schmidt (2010) found that the long-term employment outcome appeared unsatisfactory in adults with childhood-onset epilepsy, findings supported by Geerts et al. (2011)'s Netherlands study. Nevertheless, in the Finnish study by Sillanpää and Schmidt (2010), about 60% of respondents with childhood-onset epilepsy had entered employment as adults. The unemployment rate was significantly higher throughout the follow-up period among the epilepsy sample than in the general population in the study area: at 23 and 48 years of age respectively the unemployment rate was 4.9% (in 1982) and 6.2% (in 2007). Other studies confirm the impact on severity of seizures and age at onset in Spain and Korea, respectively (Marinas, 2011; Sang-Ahm, 2005). More epilepsy awareness was recommended.

Individual psychosocial functioning was associated with better employment outcomes. This was shown by Smeets, van Lierop, Vanhoutvin and Aldenkamp et al. (2007) who reviewed 24 studies on epilepsy and employment and concluded that there were complex interacting problems affecting employment such as stigma, seizure severity and psychological variables such as low self-esteem, passive coping style, and low self-efficacy. They recommended specific training interventions to improve self-efficacy and coping skills. Their conclusions and recommended strategies focused on the individual person with epilepsy whom they expected to 'accept their disorder and make personal and health-related choices that help them to achieve better employment positions in society' (Smeets et al., 2007, p. 354).

Research showed that people with epilepsy were affected by individual factors differently since they were not a homogenous group but varied by age, gender, type of epilepsy, social class, and other variables (Holland, Lane, Whitehead, Marson, & Jacoby, 2009). To

understand differences that emanated from some of these variables, Holland et al. (2009) studied 350 individuals with epilepsy who were of working age. They examined labour market participation following the onset of seizures and early epilepsy. Employment rates were calculated for the cohort and general population. Employment trajectories over four years were explored in terms of occupational social class. The relative risk of employment was calculated by clinical features of seizures and social class. People who had recently experienced a single seizure or who had early onset epilepsy experienced substantial employment disadvantage. Holland et al. (2009) recommended that greater efforts were needed to help these people return to work and stay employed.

## *Social barriers in the workplace*

While researchers cited in the preceding section dwelt on individual factors, others such as Bishop (2002) focused on social barriers to employment. A study in the USA by Bishop (2002) found that for a person with epilepsy, attaining employment often involved the negotiation of numerous obstacles, including navigating the relationship between work, epilepsy, and its treatment, often in the context of negative and uninformed attitudes and beliefs of employers and co-workers. These results underscored the complexity of the process of seeking, attaining, and maintaining work for a person with epilepsy. Bishop (2002) found that barriers included employers' fear of elevated accident rates, increased insurance rates, and concerns about workers' safety. Likewise, a study of 204 employers in the UK concluded that epilepsy created high rates of concern for 50% of employers, especially relating to the likelihood of work-related accidents (Jacoby, Gorry, & Baker, 2005). In Bishop's (2002) study, in discussing the disclosure of his epilepsy to his employer, one discussant said:

> Every job I have, as soon as they find out, there are excuses and excuses and reasons to
> throw me out the door. And really there is nothing that I cannot accomplish or that I

73

cannot do. Give me a few minutes if I have an aura or if I have a simple seizure, it's not

a big deal (p. 284).

The challenges highlighted were social in nature and related to employer attitudes, as reported in other studies. In a study of employers (n=204) across 14 employment sectors in the UK, Jacoby et al. (2005) reported that employment was one area of quality of life known to be compromised by epilepsy and that employer attitudes contributed to the employment problems of people with epilepsy. Twenty-six percent of respondents reported having experience of employing people with epilepsy; 16% considered that there were no jobs in their company suitable for people with epilepsy; 21% thought employing people with epilepsy would be 'a major issue'. Employers were uniformly of the view that people with epilepsy, even when in remission, should disclose their condition to a prospective employer. Seizure severity, frequency, and controllability were all considered important features of epilepsy in the employment context, reported Jacoby et al. (2005). Attitudes to employment of people with epilepsy were influenced by company size and type, and previous experience. However, it is worth noting that, in Jacoby et al.'s (2005) study, employers were willing to accommodate people with epilepsy, through job sharing, temporary reassignment of duties, and flexible working hours. Similar sentiments were found in the review of literature on disability and employment (Erickson et al., 2014; Jacoby & Baker, 2008; Ju et al., 2013). While other studies focused on employers, Dorota, Witkowska, and Michalak (2014) studied co-workers in Poland and concluded that stigma was prevalent and co-workers had negative views about working with a person with a disability.

## *Discriminatory experiences*

After investigating the employment discrimination experiences of 555 young people with epilepsy in the USA, researchers concluded that people with epilepsy were more discriminated

against than their counterparts with other forms of disabilities (McMahon, Roessler, Hawley, & McMahon, 2012). Unlike other studies, McMahon et al. (2012) used a comparison group of 12,663 people with other disabilities. Both groups of young people were employed in industries associated with entry-level positions, such as retail trades, manufacturing, healthcare, social assistance, accommodation, and food services, and most allegations for both groups pertained to post-hire issues, e.g., unlawful discharge and failure to provide reasonable accommodations. McMahon et al. (2012) reported that young people with epilepsy were more likely to file allegations regarding unlawful discharge and were more likely to receive a merit rating for their allegations from the Equal Employment Opportunity Commission (EEOC). Findings from the study by McMahon et al. (2012) suggested a connection between poverty and the likelihood of a diagnosis of epilepsy; the need to target certain industries for disability awareness training; the relationship between a seizure at work and termination; and the importance of worksite interventions addressing barriers to productivity and accommodation planning.

In a USA study that analysed workplace allegations of discrimination made by 5,902 workers with epilepsy, much of the discrimination was found to have occurred during employment and not before recruitment (Hawley, Roessler, & McMahon, 2012). From this study, the proportion of allegations from females was greater among the younger than the older worker, while both younger males and females with epilepsy were more likely to file allegations regarding unlawful discharge (Hawley et al., 2012).

In South Korea, Sang-Ahm (2005) studied the employability of 543 people with epilepsy and found several barriers to employment that resulted in 31% unemployment for people with epilepsy, five times more than the general population. Participants reported that they were not given jobs once their condition was known. In Poland, unemployed people with epilepsy cited lack of adequate education and frequency of seizures (Marinas, 2011). In Malaysia, Lim, Wo, Wong, and Tan (2013) studied 250 people with epilepsy and found that

gender and education impacted on employment opportunities, despite a strong economy; those who were employed were in part-time or low-paid employment.

## *Employment services*

Sung et al.'s (2014) study on vocational rehabilitation service patterns and employment outcomes of previously unemployed people with epilepsy, who had received services (n=2030), found 884 (43.5%) achieved successful competitive employment. Their results indicated that higher education levels and accessible vocational rehabilitation services were positively related to successful employment outcomes. In contrast, Sung et al. (2014) reported. having co-occurring anxiety and depression, receiving cash benefits or a prolonged period in the vocational rehabilitation system was negatively associated with employment. Other specific vocational rehabilitation services (e.g., education, vocational training, and job search and placement assistance) were also found to be significant predictors of employment. Services provided by state vocational rehabilitation agencies were proven to be beneficial in improving employment outcomes. People with epilepsy were encouraged to pursue vocational rehabilitation services to increase their chances of attaining employment (Edward, Cook, & Giandinoto, 2015; Sung et al., 2014). Sung et al. (2014) reported that employment services were helpful to improve the acquisition of work skills, make job seeking productive, and ensure employees with disabilities could work productively and retain their positions.

## *Role of self-management and resilience*

Dealing with the economic, social, political, cultural, biomedical, and psychological problems brought by epilepsy required self-management abilities from the individual (Bradley, Lindsay, & Fleeman, 2016; Day, 2008; Edward et al., 2015; Ring et al., 2016; Taylor et al., 2011). Self-management included adaptive behaviours that a person used to control seizures including compliance with treatment, safety (e.g., stop driving), and other activities aimed at reducing

triggers, argued Day (2008). Al-Adawi et al. (2003) found that knowledge of epilepsy increased a mastery of epilepsy and this reduced challenges for people with epilepsy. However, people with epilepsy did not always have correct and adequate knowledge about their condition (Al-Adawi et al., 2003; Coker, Bhargava, Elliott, & Shneker, 2008; Fitzgerald & Doherty, 2011). Resilient individuals had the potential to 'recover, adjust, resist stress and potentially thrive in the face of adversity' (Edward et al., 2015, p. 196). Psychological resilience was the ability to adapt to stressful events with good outcomes (Day, 2008). Studies by Day (2008) and Edward et al. (2015) downplayed the role of seizure frequency in quality of life and argued that resilience was more pronounced. Taylor et al. (2011) reached the same conclusion in their examination of adults with epilepsy.

Self-management was found to play a positive role in the lives of people with epilepsy supported by educational and lifestyle management programs. A study by Munn (2008) found that self-management education improved knowledge and self-confidence of adults. They were better able to deal with psychological stressors and reported better seizure control and quality of life and they had better knowledge of symptoms (Jacoby & Baker, 2008; Munn, 2008). Munn (2008) recommended the use of individualised approaches to deal with the multiple challenges of people with epilepsy, such as those shown in Table 4:4.

**Table 4.4: Techniques to foster self-management and individual resilience**

| Category | Technique |
|---|---|
| Individual factors | Self-esteem. <br> Vocational education. <br> Positive adjustment to diagnosis of epilepsy. <br> Social life skills. <br> Knowledge of epilepsy. |
| Environmental factors | Early treatment. <br> Positive family environment. <br> Counselling. <br> Peer involvement and support. <br> Psychosocial education and behavioural interventions. <br> Epilepsy and health education. |

Richardson's (2002) resiliency model presumed that, faced with adversities, like epilepsy, individuals experienced biopsychosocial disruption, after which they reintegrated in a manner that improved their resilience and reduced their vulnerability. Self-management increased coping, understanding, treatment adherence, and seizure control, all of which were important for employment (Lindsay & Fleeman, 2016; Munn, 2008).

## Epilepsy and employment in Africa, including Zimbabwe

### *African studies*

There was little information from Africa on epilepsy and employment. Only two articles focused on employment directly (Halima et al., 2017; Hounsossou et al. 2015). Three addressed employment in passing (Mushi et al., 2011; Nuhu et al., 2010; Obiako et al, 2014), while 11 dealt with issues of treatment and education.

Halima et al. (2017) studied discrimination in Senegal. Forms of discrimination reported by two-thirds of participants included job degradation, lack of promotion, and the threat of dismissal. Most (98%) people with epilepsy who participated in the study worked in the tertiary industries. Most (78%) had disclosed their condition to their employers. Twenty-four (56%) reported that work impacted on their epilepsy, while 84% reported that epilepsy impacted on their work. The researchers concluded that there was a relationship between epilepsy (seizures in the workplace) and work (stress inducing work environments).

Hounsossou et al. (2015) found negative attitudes towards people with epilepsy in Benin, despite the fact that participants had a fairly accurate understanding of epilepsy (95.3% supported mainstream education for people with epilepsy). For example, only 28.6% of respondents said they would employ a person with epilepsy, while 25% said epilepsy was contagious. However, the study did not include people with epilepsy.

Nuhu et al. (2010) found negative attitudes towards people with epilepsy and consequent social difficulties. Likewise, Mushi et al. (2011) found that people with epilepsy faced socioeconomic exclusion exacerbated by misunderstandings about epilepsy. These researchers recommended epilepsy awareness and improved treatment.

Obiako et al.'s (2014) study of 242 people with epilepsy in Nigeria found that there were limited education and employment opportunities for them: 50% had not finished school, 73% had no jobs, while 5% reported negative attitudes from employers and co-workers. They called for more awareness and psychosocial support interventions like counselling. Soumaila et al.'s (2017) survey of teachers in Niger found they held negative beliefs about epilepsy, believing it was contagious and incurable, even with modern medicine. Similarly, Morenikeji et al. (2017) found that 7% of the teachers they surveyed in Nigeria believed that children with epilepsy should not attend school. In Uganda, Duggan (2013) found that children with epilepsy and their families encountered stigma and discrimination resulting in low school attendance. Only 92 of the 162 school-aged children in the study were attending school. Likwise, Quereshi et al.'s (2017) Tanzanian study found that children's learning difficulties emanated from the stigma and poor educational support.

Doumbe, Bikek, Kuate, and Njamnsh (2017) found that a significant number of health workers in the Cameroon had incorrect knowledge of, and negative attitudes towards, people with epilepsy and some failed to treat them properly. In Guinea, Balde, Cisse, Toure, Kouyate and Balde (2017) found that a significant number of people with epilepsy preferred traditional treatments because they were cheaper though they often mixed biomedical and traditional treatments resulting in prolonged periods of seizures. Similar findings were reported in Tanzania (Mushi et al., 2011; Quereshi et al., 2017; Winkler et al., 2009). In Togo, Assogba, Waklasti, Kombate, Apetse, and Balogou (2007) found 132 people with epilepsy had low

adherence to treatment due to a lack of correct information about epilepsy. This was compounded by treatment personnel's ignorance about appropriate interventions.

## *Zimbabwean studies*

There was no research on employment and epilepsy in Zimbabwe. Available research focused on health and education issues. Seventeen research articles that indirectly related to epilepsy and employment were reviewed and their results showed issues of individual functioning, social challenges and poor access to health services.

Individual functioning was reported in three quality of life studies for people with epilepsy (Madzokere, 1997; Mielke et al., 2000; Saburi et al., 2006). Madzokere (1997) found high levels of stigma among people with epilepsy though women with epilepsy were more disadvantaged. Mielke et al. (2000) found that 36 of the 38 people with epilepsy in their sample and their carers did not believe that their epilepsy interfered with their social functioning, work performance, or relationships with others. A similar study in neighbouring Zambia found that seizures interfered with daily activities and social functioning (Birbeck, 2000). Saburi et al. (2006) reported fear, isolation, and secrecy. Mugumbate and Nyanguru (2013) measured the challenges of 60 people with epilepsy in Harare and found most were psychosocial, followed by economic and lifestyle. The most common issues were: securing an adequate income (93%), standard of living (83%), and finding and maintaining employment (78%). Related to these challenges was limited education among people with epilepsy. Saburi (2011) noted that children with epilepsy did not attend school or their attendance was poor. Families were not giving adequate support to their family members with epilepsy, especially educational support.

Social challenges were reported in a study by Vyas et al.'s (2016). the study found that stigma was a major challenge for people with epilepsy, who were often misunderstood as demon possessed. Socioeconomic challenges were linked to myths, misunderstandings, and incorrect knowledge about epilepsy (Mugumbate & Mushonga, 2013). Myths, such as the

notion that epilepsy was contagious, restricted association with people with epilepsy. Where such misunderstanding existed, even for employers who were part of this community, employing a person with epilepsy was problematic. Mielke, Adamolekun, Ball, and Mundanda (1997) reported that 55.5% of 165 teachers surveyed in a peri-urban area near Harare said they would employ a person with epilepsy; 82% said they would allow their child to play with an epileptic child; 76% would marry an 'epileptic'; 22.6% thought that epilepsy was contagious; 12.6% thought it was a form of insanity; and 0.6% thought it was caused by evil spirits. However, their sample comprised educated people who were generally positive towards people with epilepsy. Misunderstanding was also reported by Butau and Piachaud (1993) who found a lack of correct knowledge amongst parents of children with epilepsy and Dewa et al. (2014) reported high levels of stigma in Zimbabwe.

Poor access to health services was reported in other studies. For example, Manungo (1993) found that Zimbabwe's health delivery system was inaccessible, resulting in people failing to comply with epilepsy treatment. Health centres were few and far between and drugs were often in short supply. Ball, Mielke, Adamolekun, Mundanda, and McLean (2000) reported similar findings and recommended primary healthcare, health education, training of health personal in epilepsy management, and increased supply of medicines, especially first-line medicines. Mielke (2006) recommended the supply of first-choice drugs, such as phenobarbital, because of their low cost and the training of primary care nurses to compensate for the shortage of doctors. Other studies focused on the quality of healthcare and found that therapeutic drug monitoring was essential to determine whether people with epilepsy were properly medicated and taking their medication (Ball & Taderera, 2003; Nhachi & Mwaluko, 1990). Adamolekun, Levy, Mielke, and Zhande (1996) found out that EEG services were expensive but useful in confirming seizure types, thereby improving treatment. Dewa et al. (2014) found that people with epilepsy missed treatment due to a shortage of medicines and

the distance they needed to travel to access health services. Birbeck (2008) highlighted the scarcity of specialist epilepsy services in Zimbabwe. Sebit and Mielke (2005) found that one in five people with epilepsy used traditional treatments first and the same number had gone back to traditional healers following biomedical treatment due to a lack of proper health education and services. Resultantly, medical treatment was delayed or ceased leading to more complex seizures and traditional treatments contributed to reduced opportunities for people with epilepsy.

## Conclusion

This chapter reviewed literature on disability, epilepsy and employment globally before reviewing literature on epilepsy and employment in Africa including Zimbabwe. Methodologically, reviewed studies were diverse, including both quantitative, qualitative and mixed methods. However, like this study, most were urban focused. The literature review showed that globally people with disability such as epilepsy were likely to face exclusion in education, employment, health, and participation in the community due to attitudinal and policy barriers. The same situation pertained in Zimbabwe and many other African countries. The review identified some gaps in the literature. First, there is a dearth of literature on epilepsy and employment in Africa including Zimbabwe. Literature available in Zimbabwe was predominantly health focused and did not adequately deal with economic and structural dynamics that sustained stigma and discrimination. Second, there were very few social work studies with none specific to employment issues in Africa and Zimbabwe. Nevertheless, the literature provided an understanding of the management of epilepsy. The next chapter provides more information on Zimbabwe with the aim of increasing understanding of the context of this study.

# CHAPTER 5

# Context of the study: Zimbabwe

This chapter discusses the context in which people with disability seek employment and work in Zimbabwe as follows:

1. Socioeconomic context, including education, employment, health, and social welfare.
2. Cultural and religious context.
3. Policy context.

## Socioeconomic context

### *Economic and employment context*

The Republic of Zimbabwe is a landlocked country in Sub-Saharan Africa between the Zambezi and Limpopo rivers. It is bordered by South Africa to the south, Botswana to the southwest, Zambia to the northwest, Mozambique to the east, and Namibia to the west. Its capital city is Harare. The population census of 2013 recorded a population of 13,061,239 people (Government of Zimbabwe, 2012). Of these, 41% were children below 15 years, 55% formed the labour force of between 15 and 64 years of age, and only 4% were of pensionable age, i.e., older than 64 years. The census used the general minimum age for admission to employment of 15 years to provide estimates of the economically active population, though, at this age, children were expected to be in year four of secondary education in Zimbabwe; 69.8% were under the age of 30 years which meant, as with many countries in Africa decimated by AIDS and HIV and with high population growth rates, Zimbabwe had a young population. The

census found that Zimbabwe had a population growth rate of 1.1% between 2002 and 2012, as compared to 1.91% for Zambia, 0.55% for South Africa, and 1.17% world average between 2005 and 2010 (Government of Zimbabwe (2012); UNDP, 2013).

Zimbabwe's economic performance declined with GDP dropping from USD11 billion in 1998 to USD1 billion in 2008, rising to USD9 billion by 2013 despite several economic blue prints initiated to spur the economy since independence in 1980 (African Development Bank (ADB), 2013, Masaka, 2013; Mlambo, 2014). Employment figures in Zimbabwe range from 4-95% (Chiumia, 2014). These highly variable, contestable, and unreliable figures are due to political manipulation, lack of statistics keeping, and a predominantly informal economy (Chiumia, 2014). The national census recorded an unemployment rate of over 11% (Government of Zimbabwe, 2012, 2014) but the World Bank (2017) reported a much lower unemployment rate of just over 5% in 2016. In 2014, Zimbabwe's statistics agency reported an unemployment rate of 11.3%. Most people were employed in smallholder farming (4.16 million people), trade and commerce (615,000), manufacturing (250,000), education (118,000), and transport (92,000) (Government of Zimbabwe, 2014). This meant a bigger percentage was employed informally. Peasant and commercial farmers, and farm labourers, constituted 37% of Zimbabwe's labour force with 52% in other employment sectors, including manufacturing, mining, tourism, and services (Government of Zimbabwe, 2014). These figures were contested on the basis that the ZSA did not consider decent employment (Luebker's, 2008). A significant number (estimates varied from less than a million to over three million) of Zimbabwe's labour force was working in the diaspora, mainly in South Africa, Botswana, the UK, Namibia, Australia, and New Zealand, showing that despite its 16 official African languages, Zimbabwe's education system continued to be in the English-language medium, giving Zimbabweans' high mobility (Masaka, 2013; Mlambo, 2014).

### *Social and educational context*

Persistent drought and lack of formal employment, meant that poverty remained a huge challenge in Zimbabwe. According to the ADB (2013), the poverty rate increased from 42% in 1995, to 63% in 2003, and over 70% in 2014. Inequality was unsustainably high, with the Gini coefficient estimated at 57% in 2009, one of the highest in the world (ADB, 2013). The World Bank (2016) reported that 3.2 million Zimbabweans (24.6% of the population) lived in extreme poverty in 2016. Zimbabwe had a declining human development index (HDI) of 0,492 in 2013, placing it 156 in the world, a fall from 91 at the time of independence in 1980 (World Bank, 2016). The HDI was based on life expectancy, education, and income. While Zimbabwe's education rate was high with 96% completing at least three years of schooling, the highest in Africa (UNDP, 2013), its life expectancy was low. Life expectancy was reported to be 38 years in 2012 (Government of Zimbabwe, 2012).

Women in Zimbabwe experience disadvantage as the culturally patriarchal society favours men (Shoko, 2013). More men (66.8%) were in paid employment than women (33.2%) in 2012 (Government of Zimbabwe, 2012). Women were mainly involved in subsistence agriculture and unpaid domestic duties. In terms of education, men were more educated than women, with more girls (54%) than boys (46%) dropping out of school to get married or to fill care and support roles in the home. Family resources were mostly devoted to the male child, while, in some areas, girls were urged to marry at a tender age so that the family might be paid *lobola* meaning literally 'bride price' (Shoko, 2013).

Zimbabwe's education rate was the highest in Africa (UNDP, 2013). In 2012, the education system comprised 5753 primary schools and 2312 secondary schools in 2012 (Government of Zimbabwe, 2012). Public tertiary institutions included 15 universities, 14 teacher's colleges, an undisclosed number of nursing schools, eight agricultural colleges, and eight technical colleges. In addition, there were also government-run industrial, self-help colleges, and

apprenticeships or traineeships (Government of Zimbabwe, 2001b). Uniformed forces (police, prisons, army, and parks) offered training for their recruits, while other educational opportunities were available in sports and the arts. In addition, there were several private tertiary education institutions. However, most people with disabilities had not attained an education due to barriers to access, such as stigma, a lack of appropriate educational materials, and limited resources for fees and extra lessons (Choruma, 2007; Mtetwa, 2011). Children with disabilities were unlikely to start school early, attend school regularly, finish school or enrol in tertiary institutions because of low pass rates (Choruma, 2007; Mtetwa, 2011). The government promoted special education for children with disabilities although services were limited. The School Psychological Services Department assessed children who required special education and reported on their needs (Choruma, 2007). Once assessed in need of special education, they were placed in special education schools, mostly run by churches and NGOs. Government policy promoted inclusive education in mainstream schools but implementation of the policy was still at the basic stage (Mtetwa, 2011; UNICEF, 2013).

### *Health and rehabilitation context*

### *Biomedical approaches*

Public expenditure in healthcare in Zimbabwe soon after independence coupled with a good health system inherited from the colonial regime, resulted in a good health system for the country (Masaka, 2013). However, the system suffered from several years of underfunding since 1990 (Mtetwa, 2011). The Ministry of Health administered the Public Health Act through an Advisory Board of Public Health (Government of Zimbabwe, 1996). The Ministry had a National Health Strategy, which was the key national health plan. Within the Ministry, there was no specific disability or epilepsy department but these departments provided services relating to disability: The Non-Communicable Diseases Unit, the Health Promotions Unit, the

Mental Health Unit, the Rehabilitation Unit, and the Medical Practitioners Council. The Health Services Board controlled the country's biggest public hospitals – Parirenyatwa, United Bulawayo, Harare Hospital, Mpilo, Ingutsheni and Chitungwiza – and provincial hospitals – Bindura, Chinhoyi, Gweru, Gwanda, Marondera, Masvingo and Mutare.

Zimbabwe had a well-developed system of health professionals. According to the Government of Zimbabwe (2004), this system included the Medical and Dental Practitioners Council of Zimbabwe, an Allied Health Practitioners Council of Zimbabwe which included clinical social workers, a Natural Therapists Council of Zimbabwe which included acupuncturists, ayurvedic practitioners, chiropractors, homeopathic practitioners, naturopaths, and osteopaths, a Nurses Council of Zimbabwe, a Pharmacists Council of Zimbabwe, a Medical Laboratory and Clinical Scientists Council of Zimbabwe, an Environmental Health Practitioners Council of Zimbabwe, and a Medical Rehabilitation Practitioners Council of Zimbabwe. The country's traditional medicines structure was established by the Traditional Medical Practitioners Act (Government of Zimbabwe, 1981).

## *Traditional health approaches*

Traditional indigenous treatments in Zimbabwe were widely used though it faced competition from Western medicine and Christian beliefs (Waite, 2000). From a Western perspective, traditional treatments are seen as alternative or complementary, although most Zimbabweans used them together with modern healing (Waite, 2000). Even though most Zimbabweans consulted traditional practitioners frequently, the practice had neither been fully recognised by the health establishment nor resourced by the government, Waite (2000) argues. Back in 1957, an association of traditional healers, the African N'anga Association, was formed, followed by eight similar associations formed between that time and 1980 when the Zimbabwe National Traditional Healers Association was formed with the support of Dr Ushewekunze then Minister of Health, Dr Chanduka, a professor of Sociology and Dr Mazorodze, then Deputy Minister of

Health (Murray & Chavunduka, 1986; Waite, 2000). Once formed, ZINATHA fought for recognition of traditional medicine resulting in an act of parliament, the Traditional Medical Practitioners Act (Government of Zimbabwe, 1981). The act established a Traditional Medical Practitioners Council to register and regulate traditional medical practitioners. The 'practice of traditional medical practitioners' involved treatment, identification, analysis or diagnosis, without operative surgery, of any illness of body or mind by traditional methods (Government of Zimbabwe, 1981). These included herbal treatment, traditional midwifery, use of mystic or psychic powers, animal products, and a range of services provided by skilled and non-skilled healers, who also used customary and religious methods, such as faith, prophecy, and miracle healing but not witch-hunting (Waite, 2000). Witch-hunting was a controversial, money-spinning and humiliating form of traditional healing done by *n'angas* and prophets in Zimbabwe which involved identifying witches. The century old Witchcraft Suppression Act (Government of Zimbabwe, 1899), revised in 1918 and 2001, prohibited witchcraft, witch-hunting and protected those accused of witchcraft. Despite this censure, a type of *n'anga*s called *tsikamutanda* continued operating as witch-hunters (Waite, 2000).

Under the law, a registered practitioner was designed a Registered Traditional Medical Practitioner (RTMP) or Registered Spirit Medium (RSM) (Government of Zimbabwe, 1981). The law regulated traditional treatment and gave the Traditional Medical Practitioners Council powers to investigate issues of improper conduct by its registered members and discipline them. The law mandated the Council to advance research on traditional treatment but excluded religious practitioners and Eastern traditional treatments, although ZINATHA had the mandate to coordinate their practice (Waite, 2000). ZINATHA promoted the use and practice of, and research into traditional herbal and spiritual healing through research and training centres, herb farms, and clinics (Cavender, 1988; Chavunduka, 1986; Murray & Chavunduka, 1986;

Ushewokunze, 1984; Waite, 2000). Mangezi and Chibanda (2010) noted that ZINATHA played:

> a big role in the management of psychosomatic and anxiety disorders. ZINATHA has attempted to educate its members in the referral of patients with mental health problems to the formal sector. Unfortunately, there has not been much collaboration between the formal and informal sectors. Psychiatrists could do more in the training of traditional healers (p. 95).

ZINATHA assessed and registered traditional practitioners. In the 1990s, there were 24,000 traditional practitioners on its register, rising to 55,000 in 2000 (Chavunduka, 2001; WHO, 2000). It also fought for the recognition of traditional medicine as a legitimate arm of primary healthcare, on par with Western medicine clinics (Cavender, 1988; Chavunduka, 1986; Murray & Chavunduka, 1986; Ushewokunze, 1984; Waite, 2000). However, traditional medicines were not available in pharmacies or covered by health insurance; there were no factories to manufacture traditional drugs; intellectual property was not recognised; and practitioners were not paid by the government (Waite, 2000).

Other countries, such as China, reported successful stories in the use of traditional medicine; Chinese medicine was available in Zimbabwe (Waite, 2000). There were ongoing calls for research into, and funding of, traditional medicine as an indigenous, cultural, holistic, and cheaper form of treatment. The WHO (2001) called for the inclusion of traditional medicine in primary healthcare. However, though herbal treatments and spiritual healing were widely used, resistance to traditional medicine centred on false claims, mysticism, and witch hunting, and the scientific superiority and proven efficacy of biomedicine (Cavender, 1988; Chavunduka, 1986; Waite, 2000).

*Rehabilitation services offered by government and NGOs*

Zimbabwe has rehabilitation facilities that are far better than most African countries (Mandipa & Manyetera, 2014; Mtetwa, 2011). These included the Ruwa Rehabilitation Centre in Harare, which had a hospital and a vocational training, physiotherapy, and speech therapy unit and National Social Security Authority (NSSA) rehabilitation unit in Bulawayo that focused on work-related injuries and vocational rehabilitation (Mandipa & Manyetera, 2014). In Zimbabwe, there were over 20 rehabilitation institutions run by the Jairos Jiri Trust, a voluntary organisation, and five operated by other trusts, most of which were introduced during colonial years between 1890 and 1980 (Devlieger, 1995). In Zimbabwe, there were 10 'special' schools offering primary education and care services, all run by the ZIMCARE Trust, a voluntary organisation (Mtetwa, 2011). Of late, the focus had been on disability mainstreaming, and nongovernment organisations working for the inclusion of people with disabilities (SAFOD, 2015). In 2007, the Office of the Special Advisor on Disability and Rehabilitation to the President and Cabinet was established to, among other duties, run the Disability Expo to sensitise communities about disability (Mandipa & Manyetera, 2014). The Schools Psychological Services Department (SPSD), a government agency under the Ministry of Education, provided psychological services such as assessments and referrals to children with disabilities. The services of the SPSD were limited mainly to urban areas.

Zimbabwe's vibrant disability movement comprised two intertwined groups. The largest was the National Association for the Care of the Handicapped (NASCOH), an umbrella association *for* 62 associations providing services to disabled persons formed in 1969 located in Harare. The second group, and by far the most vibrant, was the Federation of Disabled Persons in Zimbabwe (FODPZ), a consumer group *of* – rather than *for* – people with disabilities, which comprised 12 member associations located mainly in Bulawayo. Despite their alignment along regional lines, NASCOH and FODPZ formed a united movement to

promote the needs and interests of people with disabilities in Zimbabwe (Mandipa & Manyetera, 2014). However, disability organisations in Zimbabwe had weak institutional capacity and were mainly limited to urban areas (Choruma, 2007; Lang & Charowa, 2007; Marongwe & Mate, 2007; SINTEF, 2003). Zimbabwe's disability activists were world-renowned, among them the late Jairos Jiri, who founded the Jairos Jiri Association in 1962 (Devlieger, 1995), and his followers Joshua Malinga, Chrispen Manyuke, Alexander Phiri, and Kudakwashe Dube. Phiri led the Southern SAFOD and Dube was a leader at the Pan African Federation of the Disabled (PAFOD) (SAFOD, 2015).

## *Social welfare and social security context*

The Ministry of Public Service, Labour and Social Services comprised three departments namely, the Child Welfare Department, Department of Social Services, and Manpower (sic) Planning and Development. The Department of Social Services' mission was to reduce poverty and enhance self-reliance through the provision of social protection services to vulnerable and disadvantaged groups in Zimbabwe, including people with disabilities. It administered the Social Welfare Assistance Act (Chapter 17:06) (Government of Zimbabwe, 1988), Disabled Persons Act (Chapter 17:01) (Government of Zimbabwe, 1992), Private Voluntary Organizations Act (Chapter 17:05) (Government of Zimbabwe, 1967), Basic Education Assistance Module, through Harmonised Social Cash Transfers, Food Deficit Mitigation, Public Assistance, Health Assistance and Employment Services Department. Government had no agency dedicated to the employment of people with disability and these services were left to individuals with the help of NGOs and rehabilitation centres.

Social services in Zimbabwe were funded through fiscal allocations, levies, donations, and grants as shown in Table 5.1. Some services were better resourced than others. For example, the National Aids Council Act (Government of Zimbabwe, 1999) provided for a board, patron, executive director, staff, and provincial branches supported by public funding.

In 1999, parliament passed a special tax act to impose an AIDS levy on formal sector employers and employees. This led to the National AIDS Trust Fund to fund AIDS programs. The fund had a budget of USD26.4m in 2011 and USD38.65 million in 2014 and proved to be a sustainable way of funding AIDS programs.

**Table 5.1: Funding and human resourcing of selected social programs in Zimbabwe**

| Social program | Funding mechanism | Administration mechanism |
|---|---|---|
| HIV and AIDS | National AIDS Trust Fund – AIDS levy 1% employer, 1% employee | National AIDS Council, a government parastatal company with branches and committees in each province. |
| Old age | Older Persons Fund | Elderly Persons Board and director. |
| Disability | Budgetary allocation, donations, and grants | National Disability Board |
| Social security | Social Security Fund – 3% employer, 3% employee | National Social Security Authority, a government parastatal company. |
| War veterans | Budgetary allocation | Ministry of War Veterans. |
| Manpower development | 1% employer's levy | Zimbabwe Manpower Development Fund (ZIMDEF) secretariat. |
| Social assistance | Budgetary allocation | Department of Social Services. |

Table 5.1 shows that HIV and AIDS programs were supported by a strong legislative framework, as was manpower (sic) development. Disability and old age were among the least supported social services. In contrast, the Disabled Persons Act (Government of Zimbabwe, 1992) provided for a board and director but had not employed an executive director or staff, and had not established a dedicated disability fund (Mandipa & Manyetera, 2014).

## Cultural and religious context

As already highlighted in Chapter 1, Zimbabwe's indigenous culture and religion, together referred as *Chivanhu,* were intertwined. *Chivanhu* comprised the sociocultural, spiritual, and

religious beliefs of indigenous Africans which undergirded society prior to the arrival of Christianity and Islam (Shoko, 2013). Kazembe (2009) classified *Chivanhu* as a distinct subculture of African religion. *Chivanhu* (14%) was practised alongside other religions, including Christianity (65%), Islam (1%), and others (1%) (Nations Encylopedia, 2016). Traditional beliefs formed understandings of the causes, effects, and management of diverse sociocultural conditions (Shoko, 2013). Although cultural beliefs had changed since colonial occupation in 1890, they remained a key pillar in shaping human understanding in Zimbabwean society (Shava, 2008). Many Zimbabweans practised Christianity or Islam together with *Chivanhu*, which resulted in a syncretic form of worship (Shoko, 2013).

*Chivanhu* centred on ancestors as the medium of communication between the living and God (*Mwari, Musikavanhu* or *Nyadenga)* in Shona or *Umlimu* in Ndebele, these being Zimbabwe's main African languages) (Shoko, 2013). Ancestors were deceased members of the clan and they were honoured in their genealogy to the last deceased person the living could remember. When an individual or family wanted to communicate with God, they did so by conversing with ancestors (Chavunduka, 1986). Prayer was usually led by the oldest male member of those present though an individual could pray to God on their own. In other circumstances, the prayer was led by a *svikiro*, a living being regarded as a spirit medium (Bourdillon, 1993). This normally happened at the clan or community level, when different members of a clan or a community of different clans prayed together. The *svikiro* might, therefore, be a member of one clan responsible for issues in that group or a community medium, responsible for various clans (Bourdillon, 1993). Each clan belonged to one animal-like totem, such as a lion, giraffe, crocodile, fish, bird, rat, or elephant, which they respected and refrained from eating, or they avoided part of an animal, such as the heart or leg. God was at the top of the hierarchy. Immediately below sat the *Gombwe* or Divine Angel, highly revered mediums representing a large geographic area (Kazembe, 2011). The *Gombwe* was followed by

*mhondoro* or *sadzinza,* a clan spirit, a clan level medium below whom were area mediums, *vadzimu*. The chief and sub-chief reported to the area medium. At the local level, traditional healers and smaller mediums oversaw spiritual issues with the help of elders. At the bottom lay individual members of society. Each individual had their talents or *mashavi* (Bourdillon, 1993; Chavunduka, 2001; Kazembe, 2009, 2011).

God was consulted during good or bad times: a good harvest, a newborn child, or a new bride or groom called for thanksgiving to God (Bourdillon, 1993; Kazembe, 2011). Likewise, drought, disease, misfortune, bad luck, death, and disability were life events that required consultation with God. Minor issues were normally dealt with by the individual or family, while major issues required intervention by the head of the clan or a spirit medium. However, in some major cases, people also consulted spiritual healers, herbalists, or *n'anga*s. Andersson (2002) observed that these were mediums with healing powers who could remove bad luck or misfortune, treat ailments, discern the cause of death, fight off evil spirits and witches, correct impairments, and offer direction in terms of their interaction with God. Bad luck was a sign of evil caused by witches, angry ancestors, or angry God. To deal with misfortunes like persistent death or disability in a family, a witch had to be found and their medicines and paraphernalia taken away by the *n'anga* or the *n'anga* performed a ritual to make witches powerless. Alternatively, a ceremony was held to appease angry ancestors or God through offerings of a hen, goat, or cow, asking for forgiveness or accepting fault (Kazembe, 2011). Murder, stealing, and incest, especially, evoked the anger of ancestors or God, so compensation to the aggrieved was part of the solution. This served as restitutive justice in traditional Zimbabwean culture (Shoko, 2013).

Men led most, if not all, cultural ceremonies, since Zimbabwean culture was largely patriarchal (Shoko, 2013). However, there were women mediums, although they were few in number. For example, Mbuya Nehanda, a female *Gombwe*, was powerful during the first war

94

of liberation in the 1890s (Kazembe, 1980). Together with her spiritual husband and another *Gombwe*, Sekuru Kaguvi, she mounted a spiritual resistance against white settlers who were led by Cecil John Rhodes. She was later executed for resisting colonial rule but is renowned her spiritual role in Zimbabwe's history. Nonetheless, there is inequality between men and women in Zimbabwean society. This makes the situation of women with disabilities particularly difficult as they must navigate the cultural discourse of gender and disability at the same time (Chifamba, 2015; Madzokere, 1997; Peta et al., 2015).

Since the arrival of missionaries during the colonial era, which began around 1500, *Chivanhu* faced competition from Christianity and Islam (Chitando et al., 2013). With the growth of Christianity and Islam, there was a shift towards organised religion. As Christian and Islamic belief systems became embedded in African societies, a syncretic form of worship developed in which indigenous and newly-introduced religious belief systems were practised alongside one another. Roman Catholic and Protestant churches were established by missionaries and, later, African independent churches grew. In time, a wave of Pentecostal churches emerged. Both the old and new religions were shaped by *Chivanhu* in one way or another. Chitando et al. (2013) said present-day prophecy in Zimbabwe was highly televised as a form of advertising and people were easily attracted to charismatic prophets demanding diverse forms of payment, including church partnership fees, consultation fees, or purchasing of anointing materials, such as oil, water, towels, bangles, bracelets, towels, or other items claimed to have healing powers. In the Pentecostal and African churches, this had become a huge business with some patients travelling from Zimbabwe to other countries, such as Nigeria, to seek spiritual healing.

While religious beliefs have changed, the dominant view of disability had not, however. In *Chivanhu*, disability was a disease of God or ancestors, a punishment to the family, clan or individual, or a condition brought by witches who were jealous or who belonged to the

95

underworld (Shoko, 2013). Interventions included exorcism, witch-hunting, or herbal treatment. The churches, too, viewed disability as a form of punishment from God, a test of one's faith by God, or simply God's condition. Solutions included faith in God, fasting, prayer, knowing and shaming the witch, and healing by prophets using anointing oil, water, or stones. In Zimbabwe, both indigenous religion and monotheistic religions viewed disability as a supernatural condition and had done little to promote evidence-based medical treatment. These values had worked against people with disabilities, relegating them to the lowest ranks in society, in the process creating social injustices against them (Shava, 2008).

## Policy context

### *International policies*

International policy instruments and programs that influenced disability work in Zimbabwe included the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006a) to which Zimbabwe was a signatory. The CPRD had 172 signatures as at January 2017 (UN, 2017). Its purpose was to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity. It provided a broad definition of disability which is quoted in Chapter 1. Initiatives by the UN included the World Disability Day and the sustainable development goals led by the UNDP. Previous initiatives included the UN Declaration on the Rights of Mentally Retarded Persons in 1971, the Declaration on the Rights of Disabled Persons in 1975, the International Year for Disabled Persons in 1981, World Program of Action concerning Disabled Persons in 1982, and the United Nations Decade of Disabled Persons from 1983-1992.

The CRPD (UN, 2006a) recognised the inherent rights of disabled people. The Convention encouraged its signatories to develop and implement policy and administrative

measures for securing disability rights, while its Optional Protocol allows for individual or group complaints about national state failure to meet the obligations of the Convention to the Committee on the Rights of Persons with Disabilities. The Convention emphasised the 'people first' perspective wherein people are not defined by their disability. It recognised disabled people's rights to participate in decision making and exercise life choices as others in society do. It championed the enforceability of these rights and, in the event of their violation, calls for action and change. It sought to remove structural barriers to participation and treats disabled people as citizens with equal rights and responsibilities in society (UN, 2006a). Ratifying countries committed themselves to combatting stereotypes and prejudices and promote awareness of the capabilities of people with disabilities, guarantee equality before the law, right to life, equal rights, and nondiscrimination. In the spirit of the Convention, the NASCOH and FODPZ lobbied the Disability Board to introduce a Disability Policy in 2010 and to ratify the CRPD (UN, 2006a), which Zimbabwe did in 2013 (Mandipa & Manyetera, 2014). Also in response to the United Nations Standard Rules on the Equalisation of Employment Opportunities for People with Disabilities of 1993, the Government of Zimbabwe introduced a policy on the Equalisation of Employment Opportunities for People with Disabilities in the Public Service but this did not have any jurisdiction over private sector employment and NGOs (Government of Zimbabwe, 2011).

## *Regional policy instruments*

Zimbabwe was a member of the Southern Africa Development Community (SADC) and the African Union (AU). The SADC was a grouping of 15 countries in Southern Africa. It has several instruments relating to disability listed chronologically in Table 5.2.

**Table 5.2: SADC disability policy**

| SADC policy | Provisions on disability |
|---|---|
| Treaty of SADC (SADC, 1992) | Prohibited discrimination on the grounds of disability. |
| Protocol on Health (SADC, 1999) | Promoted effective measures, such as community-based rehabilitation, to prevent and manage disabilities and increase access to improved technology related to assistive devices and thus remove obstacles for the equalisation of opportunities for people with disabilities. |
| Charter of Fundamental Social Rights (SADC, 2003) | Member states were required to create an enabling environment in which all persons with disabilities, regardless of the origin and nature of their disability, were entitled to 'concrete measures', including vocational training, assistive devices, transport, housing, and employment, in keeping with 'the capacities of beneficiaries' that improve social inclusion and integration. |
| Code on Social Security (SADC, 2008a) | Article 14 advocated for social security measures for people with disabilities, including safety nets (social insurance and social assistance) and equal access to benefits. |
| Protocol on Gender and Development (SADC, 2008b) | Sought to harmonise treaties like the CRPD (UN, 2006a) and contained an article on disability. |
| Principles and Guidelines Governing Democratic Elections - Principle 7(9) (SADC, 2015) | Encouraged participation of persons with disabilities in all aspects of the electoral process. The Parliamentary Forum's Norms and Standards for Elections in the SADC Region supported this principle. |

Despite this policy framework, Murungi et al. (2013) were critical of the SADC's emphasis on the biomedical approach to disability at the expense of a rights-based focus. Further, the SADC did not have a disability-specific policy instrument. The African Union (AU, formerly the Organisation of African Unity) represented 54 member countries. The AU has several policies on disability, mostly implemented by the African Commission on Human and Peoples' Rights (Combrinck & Mute, 2014). Some of these are described in Table 5.3. AU policies have been criticised for not adequately addressing the needs of vulnerable groups because they viewed these groups as homogenous (Schneider, Eide, Amin, MacLachlan, & Mannan, 2013). Schneider et al. (2013) recommended the mainstreaming of disability in AU policies.

**Table 5.3: AU policies and initiatives on disability**

| AU policy or initiative | Provisions on disability |
|---|---|
| African Charter on Human and Peoples' Rights (the African Charter) (OAU, 1981) | Contained a dedicated provision on the rights of persons with disabilities. |
| African Charter on the Rights and Welfare of the Child (ACRWC) (OAU, 1990) | Article 13(1) states 'every child who is physically or mentally disabled' has the right to special measures of protection in keeping with his or her physical and moral needs. |
| Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol) (AU, 2003) | Promoted the rights of women with disabilities. |
| Draft Protocol on the Rights of Persons with Disabilities (AU, 2015) | Completed in 2015 by the Working Group on the Rights of Older Persons and People with Disabilities in Africa, this draft protocol includes charters for women, children and young people, and people with disabilities, who are among the most marginalised on the continent, as well as a convention for displaced persons. |
| African Decades for Persons with Disabilities, 1999-2009, 2010-2019 (AU, 2002) | Promoted equal opportunities and protects the rights of persons with disabilities and encourages their full participation in social and economic development. |

Zimbabwe was selected by the then OAU to host the African Rehabilitation Institute (ARI) which collaborated with other disability institutions with a view to developing self-reliance for people with disabilities (Government of Zimbabwe, 2011). Combrinck and Mute (2014) argued that the AU had taken a medical and, at times, deficit approach in dealing with disability. In most cases, rights were based on resource availability that did conform to the CRPD (UN, 2006a). These AU policies and accompanying disability-related initiatives and programs were implemented at different levels by international, regional, and national governments through public and private welfare institutions.

*Local policies*

*Constitution of the Republic of Zimbabwe*

Zimbabwe adopted a new constitution (Act Number 20) in 2013 to replace the 1979 Lancaster House Agreement (Government of Zimbabwe, 2013). The 2013 Constitution of the Republic of Zimbabwe sets ground rules for social welfare, including the provision of social assistance programs, and provided a framework for recognition of the rights of, and prohibits discrimination against, people with disabilities. It made provision for two people with disabilities to be elected as senators in a special vote by people with disabilities (Government of Zimbabwe, 2013). Section 3 of the Constitution made recognition of persons with disabilities as one of the founding principles of the country. Section 22 (persons with disabilities) of the Constitution stated that the State must recognise the rights of persons, assist persons with disabilities and their organisations within the limits of resources, make amenities accessible, promote work and mainstream disability in development plans.

While the constitution explicitly spelt out physical and mental disabilities, it does not do so for other categories of disabilities such as neurological, sensory and intellectual, although these were assumed to fall under the broad categories spelt out. Despite weaknesses in this conceptualisation of disability, the constitution provided for the welfare of people with disabilities, at least as a promise based on 'resource availability', thus making welfare contingent on government largesse. In its favour, the constitution clearly prohibited discrimination on the basis of disability in the labour market and social institutions and made it a punishable offence, although no cases were known to have been successfully taken to court (Mandipa & Manyetera, 2014; Mugumbate &d Nyoni, 2014).

*Disabled Persons Act and draft Disability Policy*

The Disabled Persons Act (Government of Zimbabwe, 1992) stated that a 'disabled person' was:

> 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 (sic) 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 (p. 1).

This definition focused on individual impairments but omitted social barriers. The Disabled Persons Act provided for the welfare and rehabilitation of persons with disabilities, and the establishment of a National Disability Board (NDB, thereafter disability board) and Director of Disabled Persons Affairs (Government of Zimbabwe, 1992). The disability board was a statutory body comprising members from NASCOH and FODPZ, government departments, and outside experts, established under the Disabled Persons Act (Mandipa & Manyetera, 2014). Section 5 of the Act listed the functions of the disability board, including policy development, discrimination prevention, income-generation projects, community based rehabilitation services, and vocational and employment services. Section 9 of the Disabled Persons Act prohibited discrimination in employment, including in recruitment, payment of wages or benefits, advancement, promotion or retrenchment (Government of Zimbabwe, 1992).

The NASCOH and FODPZ proposed a National Disability Policy in cooperation with the disability board (Mandipa & Manyetera, 2014). The draft policy had been under government review for several years. The draft policy, with its 'policy to practice' orientation, sought to address the problem of implementation and acknowledged that, though Zimbabwe had sound and just disability legislation, service delivery and benefit provision were abysmal.

The proposed policy called for a new Department of Disability to implement legislation and related regulations and provisions. Despite having a high-level taskforce that included Dr Timothy Stamps, former health minister and presidential health advisor, the taskforce had not made much progress. Nevertheless, in its report to the UN in 2011, the Government of Zimbabwe indicated its achievements, including recognition of all disabilities according to the CRPD (UN, 2006a); a policy on the equalisation of opportunities to guard against discrimination, the Public Service Regulations Statutory Instrument 1 of 2000; an disability board and Secretariat, as well as a Disabled Persons Fund run by the disability board to provide for basic needs and loans (the disability board received USD800,000 in 2010 and USD1340,000 for 2011); and welfare grants, counselling, and awareness-raising services, and accommodation orders. The government claimed that it was paying a salary for assistants for people with disability working in the public service who needed one (Vinga, 2017). However, programs were fragmented and there was no central system to coordinate case management for people with disabilities (Mandipa & Manyetera, 2014; Mtetwa, 2011). Further, there were no monitoring and review mechanisms to inform long-term planning (Government of Zimbabwe, 2011).

*Labour Act*

Chapter 28:01 of the Labour Act (Government of Zimbabwe, 2005) stated that every employee had the right to join trade unions and worker's committees. The Act prohibited discrimination and forced labour and fostered fair labour standards and democracy in the workplace. It set conditions for contracts, termination of employment, remunerations, dismissal, retrenchment, leave, formation of employees and employer unions, collective action, formation of employment councils, regulation of employment agencies and establishes the Labour Court. Section 12(B) of the Act prohibited the termination of employment contracts without notice. If a case of unfair dismissal arose, the employee must show that they were dismissed and the

employer must prove the dismissal was fair. Dismissal procedures for each employer should be registered with authorities. If not, the employer should follow procedures for their industry registered with the National Employment Council (NEC). If the employer had no employment code or is not a member of a NEC, then it used the standard procedures stated in section 102(9) of the Labour Act. The process had the following stages: the employee was informed in writing on time, the case was heard, legal representation was allowed, and verdict was appealed by employee, where necessary.

*Manpower Planning and Development Act*

Chapter 28:02 of the Manpower Planning and Development Act (Government of Zimbabwe, 2001b) set conditions for technical, vocational, and university education and guidelines for funding tertiary educational institutions, students, and research. It established the National Manpower Advisory Council, the Manpower Planning and Development Fund. It regulated apprenticeship training and skilled worker certification. It also set powers on the Minister, which include setting fees, rebates and awarding scholarships. These roles were usually accomplished in collaboration with the Ministry of Finance. The Advisory Council advised the government on manpower development and training. It is composed of employer and employee organisations, government departments, statutory bodies and professional organisations but does not have special interest groups like DPOs. However, the Council could co-opt none-voting members. The Manpower Planning and Development Fund, also termed the Zimbabwe Manpower Development Fund (ZIMDEF) collected a 1% training levy (calculated from the gross wage bill of employers). Statutory instruments 74 and 392 of 1999 supported the administration of the fund which was used for payment of tuition, boarding fees, and wages of apprentices; payment of industrial attachment allowances to polytechnic students; infrastructural development in tertiary institutions and research. The Minister of Tertiary Education was the trustee of this fund (Government of Zimbabwe, 2001b). In theory, this fund

offered opportunities for funding fees of disadvantaged people with disabilities, programs to enhance inclusion at educational institutions, and research into disability and employment but none of these goals were reached.

The Manpower Planning and Development Act provided for apprenticeship training run by the Apprenticeship Board of the Industrial Training and Trade Testing Department (Government of Zimbabwe, 2001b). It allowed employers to designate some of their employment positions as skilled worker positions. The skilled workers then train unskilled workers. The trainees were selected, paid, tested, and certified by government. The employer's role was to provide work and supervision. Employers approached the government to register a skilled trade. DPOs could advocate for certain trades to be designated skilled, so that people with disabilities could train for and fill those positions. Those who wanted to be apprentices then applied to the Secretary of the Ministry of Tertiary Education for registration. Once registered, they applied to employers for skilled worker positions.

*Social Welfare Assistance Act*

The Social Welfare Assistance Act set conditions for application, consideration and eligibility for social assistance to persons in need and their dependants (Government of Zimbabwe, 1988). It set funding, reporting and appeal mechanisms. It gave the role of running social assistance to the Director of Social Welfare. The Director determined the type of social assistance to be given and considers applications. The assistance provided for in the Social Welfare Assistance Act included financial, rehabilitation, counselling services, provision of orthopaedic and orthotic appliances, occupational training, basic education and tertiary education fees. To qualify for this assistance, an applicant was expected to be 60 years of age, handicapped physically or mentally, suffered continuous ill health, was a dependent of a person who was destitute or indigent or incapable of looking after oneself. The financial support was usually USD20 a month or USD500 for groups who wanted to initiate self-employment projects

(Mtetwa, 2011). The Ministry set regulations detailing amounts of support to be given in consultation with the Ministry of Finance. In giving this support, the Director considered the degree of financial hardship, other sources of assistance, state of health, educational level and level of skills. In the event the applicant was not happy with a rejection or amount of support offered, they appealed to the Minister within 30 days.

The provision of basic needs was laudable, so was the focus on training but it social welfare provision had some loopholes. There was need to add medicines, tertiary education fees, carer support and community awareness or training on the list of types of social assistance to cater for people with epilepsy and others. More could also have been done to make the approach more developmental such as making the benefits reasonable enough to reduce poverty for those who were unable to work, or were unable to find work or needed support to improve their employment opportunities. The monthly grant of USD20 was a negligible amount, given that the cost of living for an individual presented as the Total Consumption Poverty Line (TCPL) for one person was USD103 in September 2014 (Zimbabwe Treasury, 2014). Despite its good intentions, the policy is flawed in its implementation due to its contingency on government largesse, the minimal benefits available, and a costly and tedious application process, since applicants must travel several times to District Social Services Offices for interviews and form submission. Further, the group allowance of USD500 was for all people in need in a whole district and not just for people with disabilities. In most cases, group numbers in each district exceeded 100, competition was high, and the system was ripe for political manipulation.

## Conclusion

This chapter reviewed the context that shaped employment in Zimbabwe. The review showed that Zimbabwe was a developing country with high poverty and unemployment levels but with

a high literacy level, and good health infrastructure. Funding of social services such as social welfare, disability, employment, health and education was minimal. Available policies did not adequately address employment needs of people with disabilities to help them overcome their disadvantage in an already competitive labour market environment. A strong disability movement was advocating for a Disability Policy and a draft had already been tabled. The most important result from the review was that, while a strong policy framework was emerging, there was no evidence of political will for effective implementation of existing policies. It seems, this is a matter of misrecognition, misrepresentation and maldistribution, as explained earlier in Chapter 2. The following chapter discusses the study's methodology.

# CHAPTER 6

# Methodology

This chapter discusses the methodology employed in this study. It begins with a statement of the research problem and outlines the aims of, and rationale for, the study. It describes the study population and the sample recruited for the research, the sampling techniques, and data collection and analysis methods used, the ethical issues involved, research process followed, and outcomes and significance of the study, ending with the study's limitations.

## Statement of the problem, research aims, and questions

Epilepsy presents a host of challenges, including economic loss to people with the condition, their families, and communities. However, in Zimbabwe, as in most communities in the Global South, it is a neglected condition, with economic needs of people with epilepsy being the most neglected. As highlighted in Chapter 2, historically, in different parts of the world, epilepsy was viewed as a contagious and horrifying spiritual condition necessitating the exclusion of people with epilepsy from society. Later it was interpreted as a biomedical condition, with disabling effects, brought about by neurological dysfunction. The spiritual and medical perspectives viewed epilepsy as an individual problem requiring herbal or medical treatment and welfare or charitable support. More recent social perspectives on disability, such as human rights and social justice approaches, highlighted the structural factors impacting on people with disabilities that prevented them from accessing education and employment. Against this backdrop, the aims of this study were to explore:

1. The lived experiences of employed and unemployed people with epilepsy in Harare.

2. The structural factors affecting people with epilepsy in Harare seeking to gain or maintain employment.

3. The strategies for addressing barriers and strengthening facilitators to employment for people with epilepsy.

Table 6.1 shows the methods used to achieve these aims. The study emphasised experiences that related to employment or unemployment. It focused on structural issues, while not ignoring individual factors.

**Table 6.1: Aims and methods**

| Aims | Method | Data collection tool | Participants |
|---|---|---|---|
| 1-3 | In-depth interviews | Interview guide | 30 people with epilepsy |
| 2-3 | Focus group discussion | Focus group discussion guide | 7 service providers |

## Research site

Data were collected at the ESF, a nongovernment organisation already described in Chapter 2. The ESF was selected as a study site because it provided the researcher with easy access to its service users and providers, being the main support organisation for people with epilepsy in the country. People with epilepsy in Zimbabwe often did not disclose their condition and it was difficult for researchers to identify them, except through institutions such as the ESF. This 'information rich' (Creswell, 2012, p. 206) study site offered an ideal location for the in-depth exploration of the employment-related experiences of people with epilepsy.

## Research population

As of June 30, 2014, the ESF had a membership of 1,600 people with epilepsy, of whom 640 (40%) were between 15 and 64 years. The study sample was drawn from this economically active group. Though the ESF did not have up-to-date employment records, its 2014 figures showed that 64 (10%) of the 640 members of working age indicated they were employed at the time of their registration. Of these, about 300 members were living in Harare. These figures had changed slightly when data collection commenced in September 2015, when the membership had increased to 1,700. Since the register had not yet been screened for 2015, the number of members of working age and their employment status was not known. It was also not possible to determine who had left the organisation.

## Research sample

### *In-depth interview participants*

### *Inclusion criteria*

The study sample was purposively selected. The inclusion criteria were: (i.) people with epilepsy registered with the ESF; (ii) between the ages of 15 and 64 years; (iii) living in Harare. Thirty people who met the inclusion criteria were selected for the semi-structured in-depth interviews. Of the 30 participants, 14 were employed and 16 unemployed; 13 were female and 17 were male. It was not possible to include an equal number of males and females, or of employed and unemployed participants, since the sample was selected on availability until the target of 30 had been reached.

## Focus group participants

To supplement the in-depth interview data, a focus group discussion was conducted with service providers (n=7) employed by the ESF based on consent and availability. The service providers included three social service workers, two health workers, and two advocacy workers. The service providers were included to; (i) focus their attention on employment issues, not usually a major preoccupation of their support work, (ii) get their opinions on the experiences of people with epilepsy with whom they worked, and (iii) this form of triangulation was an opportunity to get service provider perspectives on the strategies they used and those suggested by interview participants.

# Data collection

## Preparation for data collection

The data collection methods included in-depth interviews with people with epilepsy using a semi-structured interview guide and a focus group discussion with service providers to ensure as accurate an understanding as possible of the employment experiences of people with epilepsy and enhance the trustworthiness (validity) of the findings (Creswell & Miller, 2000). Creswell and Miller (2000) explained that validity related to how accurately the account represented the participants' realities or experiences. Procedures to enhance validity included member checking (Creswell & Miller, 2000). These checks enhanced the credibility of the findings (Lincoln & Guba, 1985). Participants were invited to review their transcripts and codes for data analysis. Another way in which validity was enhanced was by staying as close as possible to participants' accounts of their experiences. Cognisant of the need for reflexivity made the researcher aware and explicit about possible bias and how to counteract it. This was achieved red through keeping a diary to record the researcher's reflections, assumptions,

beliefs, values, and biases that could have influenced the research process (Creswell & Miller, 2000).

Semi-structured interviews were preferred to unstructured interviews to ensure that the discussion focused on structural factors. The in-depth interviews (n=30) were conducted to collect data on their experiences of living with epilepsy, including how the participants had learnt to manage their epilepsy, how it had shaped their education and skills acquisition, and job-seeking and employment prospects. The researcher explored the facilitators and barriers to employment they had encountered, and their suggestions on effective strategies to improve their employment outcomes. To enlarge understanding of the participants' experiences, the researcher conducted a focus group with seven ESF service providers at the ESF. This added to the trustworthiness and credibility of the data (Tetnowski, 2015; Yin, 2016).

The researcher received a letter of support for the research from the ESF in 2014 (see Appendix 11 and 12) and fieldwork commenced following ethics approval in October 2015. The researcher visited the ESF to explain the research process and hand over the organisational information statement and consent forms (see Appendices 2 and 3).

## *Semi-structured, in-depth interviews*

### *Pre-testing the interview guide*

One of the ways to increase methodological reliability in qualitative research is to pre-test the interview guide (Hurst et al., 2015). While arranging for the interviews, the researcher tested the semi-structured interview guide on two people with epilepsy residing in Harare, who were not members of the ESF. The pretesting process encompassed seeking consent, interviewing, and transcribing to improve the interview guide, if necessary, test the recording equipment, and familiarise the researcher with the interview processes (Hurst et al., 2015). Following pretesting, the researcher refined the questions and added sub questions to assist with probing

for further detail (Creswell, 2012). For example, the test participants found the question asking respondents to describe their periods in 'formal' or 'informal' employment confusing, as they did not understand the meanings of the words 'formal' and 'informal' and found the interview 'a tough examination'. The researcher increased the number of prompts to ensure clarity (see Appendix 7).

The summary in Appendix 7 reflects the schema the researcher developed to remind him of the key issues to be discussed during the interview and, more importantly, to standardise the language used across the interviews. Also, following the pretesting, the researcher realised that it was likely some participants would prefer the interview to be conducted in English and Shona. The researcher translated the main research questions, prompts, and probes into Shona, as shown in Appendix 7. This was important because participants spoke English and Shona, and used them interchangeably.

Those interested in the study contacted the researcher via email, phone calls, chats, or text messages. The researcher discussed the purpose of the research and gauged their willingness to participate in an in-depth interview. The researcher sent the consent form and information statement via email or made them available for collection at the ESF. Participants returned the signed consent forms in sealed envelopes to the researcher c/o the ESF. This process continued until 30 participants had been recruited. Upon receipt of the consent form, the researcher contacted the participant to arrange a tie and venue for the interview.

*Interviewing procedure*

The researcher started each interview by confirming the participants' consent to participate in the research and assuring them that: (i) participation was voluntary; (ii) they could withdraw at any time; and (iii) no negative consequences would ensue if they chose to withdraw. The participants were reminded of their voluntary participation and that the interview would be recorded.

Three participants did not consent to having their interviews audio recorded; all agreed to a follow-up interview, if necessary, and were happy for the ESF to provide information, where necessary. The consent process enabled the researcher to allay anxieties about the research, clarify requirements, and avoid distress (Ahern, 2012). The researcher ensured that the participants understood what participation entailed.

Once the researcher was sure the interviewee was comfortable with proceeding, he began the interview. As a skilled social worker, the researcher had interviewing skills in listening, asking questions, observing, refraining from debate, and maintaining a nonjudgmental attitude (Creswell, 2012). After each interview, the researcher listened to the recording to ensure the data was audible, detect anomalies, and determine whether telephone follow-up would be needed (Creswell, 2013). The researcher conducted seven follow-up interviews.

The researcher asked willing participants to check their transcripts to enhance the credibility and dependability of the data (Tetnowski, 2015). Member checking happened at three levels: (i) Four participants asked to listen to the audio recording soon after the interview with the interviewer; (ii) Seven participants asked to review a copy of the raw interview transcript; and (iii) 14 participants reviewed the edited draft of the interview transcript. The researcher then used any new information received to produce a final transcript for each participant.

The researcher conducted 24 interviews at the ESF, two at the participants' workplace, two at a restaurant, one in a park, and one at the participant's home. The ESF suited most participants, who visited the ESF for different services. Most participants arranged the interview appointment to coincide with one of their regular visits.

At the end of each interview, the researcher thanked participants for taking their time to talk to him and confirmed whether they required reimbursement for their transport costs.

The researcher did this on the advice of a service provider, who said that participants might not tell the researcher they expected reimbursement. The participants who requested reimbursement received USD2, on average, too little to constitute coercion (Creswell, 2012; Khama & Ndebele, 2014).

The transcription or audio recordings of the interviews were reviewed to prepare an initial set of main themes for presentation in the focus group discussion. These were reviewed by his supervisor.

## *Focus group discussion*

### *Preparation for focus group*

Prior to the focus group discussion, the researcher emailed an information statement and informed consent form to nine potential service-provider participants employed at the ESF, who requested further information on the purpose and focus group procedure. A suitable time and place for all participants was established. The researcher emailed the preliminary report (Appendix 1) to each of the focus group participants together with the focus group discussion guide (Appendix 10). The report summarised the themes from the 28 interviews with names and identifiable descriptors removed to preserve the interviewees' anonymity (Creswell, 2012). The themes were listed in categories, including service-users' employment experiences, barriers and facilitators to employment, and coping strategies. The focus group guide covered complementary areas the researcher wanted to explore with service providers to solicit their views, as follows:

1. Views on experiences of people with epilepsy.
2. Views on barriers and facilitators to employment, and issues of access, stigma, and discrimination.
3. Views on support strategies suggested by people with epilepsy.

*Focus group procedure*

After exchanging greetings, the researcher/facilitator welcomed participants and ensured everyone was within reach of the audio recorder and microphone. At this point, the researcher checked that participants understood the purpose of the study and what was required of them. They were assured that their participation was entirely voluntary and no negative consequences would ensue should they wish to withdraw at any point in the process.

To warm up, the researcher asked the participants to introduce themselves and talk about their work. The researcher then summarised the key themes and read each statement to initiate discussion. In the beginning, participants did not say much. The researcher had to introduce some icebreakers, explaining that any information was useful for the study. The participants then started sharing their views and engaging in constructive discussion and debate. They deliberated on the statements, a process lasting 89 minutes, 21 minutes more than anticipated, due to the time taken in circulating the only microphone. Following the discussion, the researcher thanked the participants and advised that the focus group transcriptions would be distributed for checking to ensure the accuracy of the data captured (Tetnowski, 2015).

## Data analysis

Once updated, the researcher asked participants to check the transcipts (Tetnowski, 2015) and made changes, as necessary to, for example, dates of events in one interview. Only a few changes were necessary. For example, in one of the interviews, a participant had attributed the actions of a co-worker to the employer and co-worker simultaneously, making it difficult to discern to whom the actions should be attributed. During member checking, the participant attributed the actions to the co-worker and not the employer. The researcher then analysed the data through thematic analysis. He read the transcripts several times to familiarise himself with the data (Braun & Clarke, 2006; Charmaz & Bryant, 2010; Saldana, 2008) and analysed the

interview and focus group data separately. The findings from the focus group discussion deepened understanding of themes that emerged from the initial manual analysis of the interview data. This process is illustrated in Figure 6.1. The researcher noted the emerging codes. These were reflected in the preliminary report for the focus group discussion.

**Figure 6.1: Data collection and analysis process**
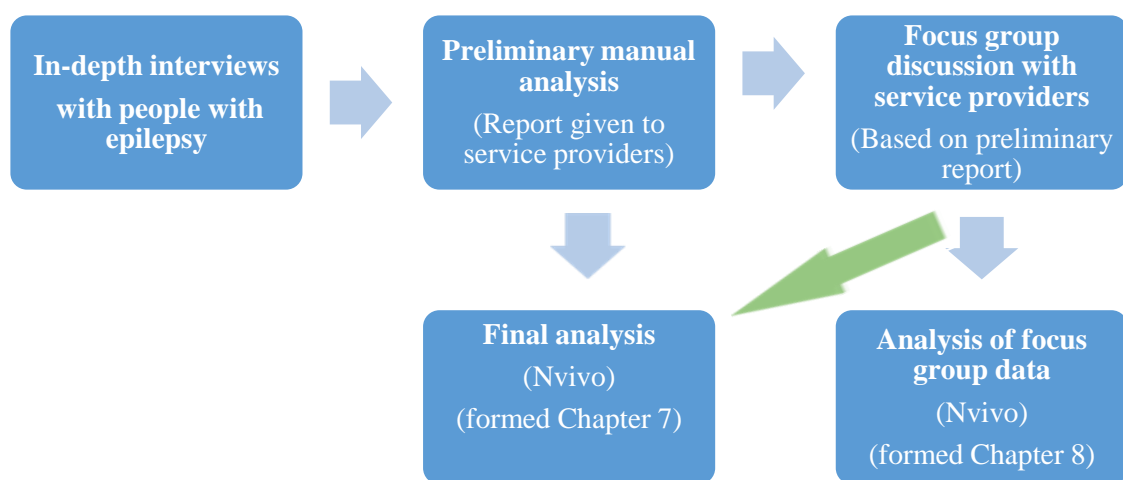


The researcher loaded the 30 transcripts into NVivo and coded the data, resulting in 42 initial codes. The researcher used the words and language of the participants to compile the codes and stay close to the participants' accounts (Yin, 2016). He grouped them into broad themes matching the study's three research questions relating to employment experiences, barriers and facilitators, and strategies. At the end of this process, 19 focused codes emerged. Axial coding was applied to refine these themes and sub-themes and identify exceptions (Braun & Clarke, 2006; Charmaz & Bryant, 2010) resulting in six main themes, each with two to four categories. The researcher then interpreted the main themes and categories thus identified considering the theory and literature review to determine whether common or exceptional

experiences had emerged for this study sample (Saldana, 2008). This data analysis process showed that the researcher applied a 42:19:6 ratio in developing the nodes, as shown in Figure 6:2. Writers have recommended different numbers. For example, Creswell (2009) recommended 5:25:5, while Lichtman (2013) suggested 80:15:5. Both Creswell (2009) and Lichtman (2013) suggested that the ratio would depend on the amount of data collected and the number of research questions. This was the case in this study.

**Figure 6.2: Coding process**



Analysis of the focus group data started with two questions on their views on: (i) experiences and factors, and (ii) effective strategies, in line with the preliminary report prepared for the discussion. The analysis produced a total of 14 initial nodes that were further merged into axial codes that became the eight themes. No focused codes were created because the initial codes were few.

## Ethical issues

The researcher was sensitive to the ethical issues in this qualitative study, which involved time-consuming, lengthy face-to-face dialogue (Creswell, 2012; Musesengwa, 2014) and aware that the quality of the data collected during the interview would depend on the participants' trust in him (Yin, 2016). The researcher was cognisant that the location of the interviews − at work or public or private spaces − raised ethical issues relating to confidentiality and access. Of concern

was that the participants could be relatively easily identified by the ESF staff, even though they were interviewed outside ESF.

The National Statement on Ethical Conduct in Human Research of Australia guided the researcher through the ethics approval process, which began with training in the use of the UON's online application portal and the ethical protocols required prior to the commencement of the research (UON, 2016). The researcher then sought ethics approval for the study. The study was approved on October 16, 2017, after six months. The Protocol Number was H-2015-0145. At the time of the research, the University to which the researcher was affiliated in Zimbabwe had no formal and rigorous institutional review board. This was the same with most, if not all, universities in the country. This weakness was not peculiar to Zimbabwean education and research institutions but applied to most African countries (Ndebele, Mwaluko, Kruger, Ouwe, Oukem-Boyer at al., 2014). Two institutions dealt with research ethics in Zimbabwe: The Research Council of Zimbabwe (RCZ) and Medical Research Council of Zimbabwe (MRCZ) established under the Research Act (Government of Zimbabwe, 1986).

Verbal and written consent was sought from participants, as already discussed. Participants were informed that their transcripts would be de-identified, their names would not be used in reporting on the research, and the information shared would not be conveyed to anyone, including ESF staff, without their prior consent. In ensuring anonymity and confidentiality, participants were allocated numbers during data collection, which were later converted to the pseudonyms used in this report.

The anticipated possibility that a participant might have an uncontrolled seizure materialised. One participant had a seizure while waiting to be interviewed and was assisted by the nurse. The participant had mistakenly left his afternoon medicines at work. The nurse explained that the participant showed signs of anxiety and this could have triggered his seizure. The researcher suggested delaying the interview or moving it to another day, but the participant

chose to continue with the interview as arranged. The interview proceeded smoothly. In line with the duty-of-care recommendations of research at the UON, the researcher remained mindful that this scenario might repeat itself with other participants. The researcher felt obliged to find information from the ESF about four participants who had requested their interview outside the ESF. The researcher asked the nurse about their level of seizure control. All were fully controlled. The researcher went ahead with the interviews at the selected venues without incident.

Bioethics stress the importance of the principle of non-maleficence, that is, removing existing harm or preventing possible harm (Musesengwa, 2014; Ng, Crawford, & Chur-Hansen, 2014). The researcher provided information to participants and referred them to the ESF for counselling or assessment, as needed. One such case was a participant who had talked about being too aggressive towards co-workers and law-enforcement agencies. The researcher provided information to the participant to seek help from the ESF about her aggression and counselled her to deal with co-workers and law-enforcement agencies in a manner that did not cause problems for her.

Each participant was provided with a unique number during the data collection and analysis phases and given pseudonyms for reporting purposes. To ensure confidentiality, any other identifiable details, such as occupation, were replaced, e.g., with other occupations at the same level as the original.

The research raised some power imbalance issues. Although the researcher had no professional relationship with the ESF at the time of the study, he had previously worked with some participants and service providers between 2005 and 2011 as a co-worker and supervisor. As such, he had a pre-existing relationship with some ESF service providers and service users. In the proposal, and during supervision meetings, the researcher clearly declared prior work experience and encounters with people with epilepsy. Further, to pre-empt any possible

119

problems, the researcher made it clear on the information statements that he would engage with participants as an academic at Bindura University, where he was employed, and as a PhD student researcher at the UON. The information statements provided clear assurance that any decision regarding participation would not affect existing relationships. This ensured a non-invasive approach (Creswell, 2012), and the researcher only visited ESF for research purposes.

Related to power issues, was the issue of positionality. For Yin (2016), the researcher's position formed his worldview, including his beliefs and passions, especially in relation to the topic under investigation. This strong connection between the researcher and research problem needed to be made explicit in qualitative inquiry lest the researcher bias the research process (Hewitt, 2007; Yin, 2016). Hence researcher reflexivity was needed (Hewitt, 2007; Saldana, 2008). Throughout the study, the researcher remained aware that, as a member of the society being studied, and as an academic, his attitudes and experiences could affect the way he framed questions, interacted with participants, and interpreted the data. Through the process of reflexivity, the researcher ensured that data collection and analysis and research reporting stayed true to the participants' accounts. The researcher remained mindful of his positionality as a professional and his power in relation to participants. He recorded his reflections, mistakes, fears, ideas, and confusions in his research journal throughout the data collection, analysis, and reporting process (Creswell, 2013; Tetnowski, 2015; Yin, 2016).

## Limitations of the study

This study had several limitations. First, the study involved people with epilepsy who were already receiving services from the ESF. Hence, it included a sample of people who had controlled epilepsy. This selection bias meant the findings might not reflect the experiences of most people living with epilepsy in Zimbabwe. Nonetheless, by selecting an economically

active group, this small-scale exploratory study yielded rich data on the employment experiences of people with epilepsy and found similarities with international studies.

Secondly, there was a likelihood that service providers might have been influenced by the preliminary report prepared for them prior to the focus group. However, its purpose was to deepen understanding of the interview findings and provide additional insights into the service-users' experiences.

Lastly, the study was designed to examine structural barriers to employment for people with epilepsy without much focus on individual and clinical factors. It was clear that some participants faced socioeconomic disadvantages and uncontrolled seizures but they seemed to have better employment outcomes than reported in other studies. Though this was attributed to their resilience, in-depth study of individual factors would be needed to confirm this conclusion. Despite these limitations, the methods chosen to address the research questions yielded valuable data, as discussed in Chapters 7 and 8.

## Conclusion

This chapter described the methodology employed in the research exploring the experiences of people with epilepsy in Harare, Zimbabwe. The study outlined the study's goal to enlarge understanding of the structural factors influencing employment outcomes for people with epilepsy and the strategies they used to access employment. It described the study's participants and data-collection and analysis methods. It ended with a discussion of the ethical issues involved and the limitations of the study. The next chapters discuss the study's findings beginning with the in-depth interviews with people with epilepsy in Chapter 7.

# CHAPTER 7

# Findings: People with epilepsy

This chapter presents the findings from the semi-structured, in-depth interviews in which the researcher explored the participants' (n=30) experiences of living with epilepsy, the factors that influenced their employment outcomes, and strategies for improving their employment opportunities. The chapter begins with a description of the participants' demographic characteristics then discusses the findings under seven main headings:

1. Experiences and factors relating to beliefs, reactions, and practices.

2. Experiences and factors relating to gaining work skills.

3. Experiences and factors relating to seeking jobs.

4. Experiences and factors relating to the workplace.

5. Experiences and factors relating to support services.

6. Experiences and factors relating to self-management.

7. Suggested strategies.

## Demographic characteristics of participants

In summary, the participants' demographic characteristics were as follows:

- Their age range was 19 to 52 years, with a mean of 33 years.

- 16 had experienced generalised seizures, eight absence seizures, and six partial seizures.

- 21 had fully controlled epilepsy.

- 18 had childhood-onset epilepsy.

- 13 were females and 17 were males.

- 29 were taking anti-epilepsy medicines.

- 18 were single and 12 were married.

- Five had a primary school education, nine secondary, 11 college, and five university.

- 14 were employed and 16 unemployed.

## *Treatment and seizures*

All but one of the 30 participants interviewed were receiving treatment and 21 described their seizures as controlled. The participant who was not on treatment was still at the diagnosis stage. The participant had indicated an unwillingness to undergo treatment as he was not sure whether he had epilepsy or was under an evil spell. As shown in Table 7.1, 18 participants had experienced their first seizures during childhood (0-18 years) and 11 during adulthood. Notwithstanding the new classification of epilepsy published by the ILAE (Fisher et al., 2016), participants experienced generalised (n=16), absence (n=8), and partial (n=6) seizures. However, there was no record of changes following medical treatment. As highlighted in Chapter 2, the symptoms of generalised epilepsy included tonic-clonic seizures affecting the whole body, partial seizures affecting part of the body, and absence seizures involving brief lapses of consciousness.

**Table 7.1: Age at onset of seizures**

| Age at onset of epilepsy | Employment status and gender | | | | | | |
| | Employed (n=14) | | | Unemployed (n=16) | | | |
| | Female | Male | Sub-total | Female | Male | Sub-total | Total |
|---|---|---|---|---|---|---|---|
| Childhood 0-18 years | 5 | 4 | 9 | 2 | 7 | 9 | 18 |
| Adulthood over 18 years | 2 | 3 | 5 | 4 | 3 | 7 | 12 |
| Total | 7 | 7 | 14 | 6 | 10 | 16 | 30 |

*Education and training*

Maximum level of education attained by both males and females and the number employed or unemployed, as well as the gender of participants is shows in Table 7:2. As shown in Table 7.2, three female – Mambe, Masiziba, and Agnel – and two male participants – Kocho and Rune – had primary school education; 19 had the minimum of five secondary-level passes that would classify them as employable, with 11 of these having a diploma. Four female – Hadeel, Ashley, Simbi, and Munya – and one male participant – Bilaal – had a university degree. The vocational qualifications and other training that participants had received included journeyman in building, welding, nurse assistant (termed nurse aid in Zimbabwe), and running small income-generating projects.

**Table 7.2: Education level, employment status, and gender**

| Maximum educational level attained | Employment status | | | | | | |
| | Employed (n=14) | | | Unemployed (n=16) | | | |
| | F | M | T | F | M | T | Total |
|---|---|---|---|---|---|---|---|
| Up to primary school level (Grades 0-7) | 0 | 0 | 0 | 3 | 2 | 5 | 5 |
| Up to secondary school level (Forms 1-4) but did not finish or pass examinations (less than five subjects) | 0 | 2 | 2 | 1 | 3 | 4 | 6 |
| Passed ordinary level examinations (five subjects) or completed high school (forms 5-6) | 0 | 0 | 0 | 1 | 2 | 2 | 3 |
| Attained a trade qualification, e.g., diploma | 4 | 4 | 8 | 1 | 2 | 3 | 11 |
| Attained a university degree | 3 | 1 | 4 | 0 | 1 | 1 | 5 |
| **Total** | 7 | 7 | 14 | 6 | 10 | 16 | 30 |

Key: F=Female, M=Male, T=Total

Table 7.3 shows the participants' skills in different fields. Eight had government accredited diplomas or certificates, while six had trained at private colleges and another six had received informal training at support organisations or a church.

**Table 7.3: Vocational qualifications (non-degree)**

| Qualification and description | Institution | Number |
|---|---|---|
| Teacher (primary school) | Government institution | 3 |
| Pharmacy | | 1 |
| Security | | 1 |
| Journeyman | | 2 |
| Nursing | | 1 |
| Media | Private colleges | 1 |
| Office management | | 2 |
| Insurance | | 1 |
| Retail work (computer/till operation) | | 2 |
| Carpentry | Apprenticeship (government) | 1 |
| Nurse aid training | Red Cross | 2 |
| Welding | Employer work-based training | 1 |
| No qualification | | 1 |
| Total | | 25 |

## *Individual profiles*

Participants' ages ranged from 19 to 52 years with a mean age of 33 years; 18 were single and 12 were married. Most participants were staying with their parents or guardians. The individual characteristics of each participant are summarised in Tables 7.4 and 7.5 as follows: Employed female participants (n=7); employed male participants (n=7); unemployed female participants (n=6); and unemployed male participants (n=10)

## *Job aspirations, occupation, and income*

Three participants – Ashley, Mambe, and Rugare – chose not to respond to questions about their childhood aspirations. When asked why, Ashley said she had not had any career aspirations as a child. As shown in Figure 7.1, the careers mentioned most often were nurse (n=5), office manager (n=4), and medical doctor (n=3). The employed participants (n=14) included three teachers, two nurses, a bank consultant, security officer, professional welder,

hotel worker, professional painter, researcher, retail manager, office manager, and housekeeper.

**Table 7.4: Characteristics of employed participants (n=14)**

| Participant | Characteristics |
|---|---|
| **Employed female participants (n=7)** | |
| Saru | A 39-year old with adult-onset fully controlled epilepsy. Highest qualification was a college diploma. A government worker who was dismissed from a private sector job because of epilepsy. |
| Thandiwe | A 42-year old with teenage-onset fully controlled epilepsy. Highest qualification was a college diploma. A government worker who had worked in private sector. |
| Mucha | A 32-year old with childhood-onset partially controlled epilepsy. Highest qualification was a college diploma. A government worker. |
| Hadeel | A 32-year old with childhood-onset partially controlled epilepsy. Self-employed worker. Highest qualification was a university degree. Did several jobs before and dismissed at two because of epilepsy |
| Ashley | A 46-year old with adult-onset controlled epilepsy. Self-employed. Highest qualification was a university degree. Left previous job because of epilepsy. |
| Grace | A 48-year old with teenage onset controlled epilepsy. A government worker. Dismissed from a similar job during internship. |
| Simbi | A 35-year old with teenage onset partially controlled epilepsy. Highest qualification was a university degree. Dismissed from two jobs due to epilepsy. |
| **Employed male participants (n=7)** | |
| Munya | A 33-year old with adult-onset fully controlled epilepsy. Was working in the financial sector. Highest qualification was a university degree. Previously dismissed from three jobs because of seizures. |
| Rugare | A 24-year old with childhood-onset fully controlled epilepsy. Highest qualification was a professional certificate. Was a government worker. |
| Rufu | A 30-year old with teenage-onset partially controlled epilepsy. Highest qualification was a diploma. Was a government worker. |
| Lameck | 28-year old with adult onset fully controlled epilepsy. Highest qualification was a diploma. Was working in administration in a private company. |
| Ishmael | A 37-year-old with adult-onset partially controlled epilepsy. Highest qualification was a professional certificate but was training to gain a diploma. Was a government worker. |
| Edson | A 26-year old with childhood-onset partially controlled epilepsy. Had no ordinary level passes or any other qualifications. Was working in retail sector. |
| Farai | A 32-year old with childhood-onset partially controlled epilepsy. Did not pass ordinary levels and an apprenticeship course. Was employed as a maintenance worker. |

**Table 7.5: Characteristics of unemployed participants (n=16)**

| Unemployed female participants (n=6) | |
|---|---|
| Nyari | A 39-year-old with adult-onset, fully controlled epilepsy. Had a secondary school certificate. Previously worked in government. |
| Tindo | A 33-year-old with adult-onset controlled epilepsy. Did not pass all required five ordinary level subjects to gain a secondary school certificate. Had a diploma. Worked in retail shops before but was underpaid and felt underrated. |
| Zoey | A 24-year old with childhood-onset fully controlled epilepsy. Did not pass all required five ordinary level subjects to gain a secondary school certificate. Previously worked as till operator in a retail shop. |
| Mambe | A 52-year-old with adult onset, controlled. Had no educational qualifications. Previously worked as a domestic worker. |
| Masiziba | A 19 years-old with childhood-onset partially controlled epilepsy. Had no educational qualifications. Had never been formally employed. Was informally trained as a tailor. |
| Agnel | A 42-year-old with adult-onset, fully controlled epilepsy. Had no educational qualifications. Had never been formally employed. Was self-employed as small-scale retail trader. |
| Unemployed male participants (n=10) | |
| Milton | A 32-year-old with fully controlled childhood-onset epilepsy. Had secondary school certificate. Previously worked as a health worker. Was self-employed as small-scale retail trader but did not consider himself as employed. |
| Gari | A 29-year-old with childhood-onset fully controlled epilepsy. He did not pass ordinary level examinations. Had done a specialised art course. Was self-employed as an artist. Had not been formally employed. |
| Sanga | A 27-year-old teenage-onset uncontrolled epilepsy. Had no educational qualifications. He was a trainee technician. Had never been employed formally. |
| Mberi | A 40-year old with adult-onset, partially controlled epilepsy. Had a secondary school certificate. Did on-the-job training for professional welding. Worked as a professional welder for two companies but was retrenched. |
| Rune | A 29-year-old with childhood-onset, partially controlled epilepsy. Had no educational, tertiary qualifications or formal work experience. Was doing small domestic jobs for pay, but was finding it difficult to get bigger household jobs. |
| Kocho | A 26-year old with childhood-onset uncontrolled epilepsy. Had no educational, tertiary qualifications or formal work experience. |
| Bilaal | A 32-year old with adult-onset controlled epilepsy. Had a university degree but was doing small self-help jobs and had never had a formal job. |
| Gab | A 29-year old with childhood-onset partially controlled epilepsy. Had no educational qualifications since he did not finish secondary school. Worked as a small-scale farmer, supplementing his income with retail trading but this is still not earn enough to live on. |
| Derry | A 34-year old, with adult-onset, fully controlled epilepsy. Did not pass ordinary level examinations. Was self-employed as small-scale retail trader working from home. Retrenched from two previous formal jobs. |
| Tonde | A 28-year old with childhood-onset, partially controlled epilepsy. Did not pass ordinary level examinations. Previously worked as a private security officer and assistant technician but was dismissed. Was self-employed as small-scale retail trader. |

Of those who were unemployed (n=16), 11 relied on a combination of self-help and family support. One unemployed participant, Nyari, received three pensions (from her deceased husband, mother, and father), which she supplemented with self-help activities. The types of self-help activities included roadside vending, (n=3), retail trading (n=4), artistic painting (n=1), domestic work (n=1), selling computer accessories (n=1), and farming and fish vending (n=1). None of the participants was receiving a government grant, even though periods of unemployment had varied from one day to several years.

**Figure 7.1: Interview participants' work aspirations**



## Experiences and factors influencing employment

This section discusses the experiences and factors that influenced gaining or maintaining employment, as shown in Table 7.6. The experiences related to beliefs, reactions, and practices; gaining work skills; job seeking; workplace attitudes and practices; support services, and self-management.

**Table 7.6: Experiences and factors influencing employment**

| Experiences relating to: | Influencing factors |
|---|---|
| Beliefs, reactions, and practices | Knowledge of epilepsy.<br>Social reactions.<br>Treatment practices. |
| Gaining work skills | Primary and secondary education.<br>Tertiary education and training. |
| Job seeking | Social networks.<br>Employment services.<br>Welfare and disability services.<br>Economic environment. |
| Workplace attitudes and practices | Attitudes of managers.<br>Attitudes of co-workers.<br>On-the-job support and adjustment.<br>Gender roles. |
| Support services | Informal sector services.<br>Health services.<br>Legal services.<br>Nongovernment services. |
| Self-management | Vulnerability.<br>Individual resilience. |

## *Experiences and factors relating to beliefs, reactions, and practices*

Participants' experiences showed that beliefs about, reactions to, and practices surrounding people with epilepsy influenced their employment opportunities in several ways, including delaying seizure control and reducing social interaction. Most influential were knowledge of epilepsy, social reactions, and treatment practices, as discussed below.

### *Knowledge and beliefs*

Participants recounted how people lacked accurate knowledge about epilepsy and viewed it as a supernatural condition, which they described in Shona as *mamhepo* (evil spirit or demons), *ngozi* (avenging spirit), *uroyi* (witchcraft), *jambwa* (curse), *chisingarapike* (untreatable), *munyama* (bad luck or misfortune), and *chivanhu* (cultural condition). As a spiritual condition,

they believed epilepsy was sign of God's or the ancestors' wrath that had to be treated through spiritual rituals by *n'angas* (traditional healers or herbalists), or prophets. Understanding the condition in this way led most participants' families to seek cultural and religious treatment for their seizures. It instilled fear, doubt, and stigma. For example, Thandiwe's husband viewed her epilepsy as a curse that the family should keep secret from others. Such family reactions were not peculiar to Thandiwe. Edson said, 'I don't usually mention that I have epilepsy, so do my family'. When probed why this was so, Edson responded: 'How do you feel if they say it's your father's goblins that are making you sick?' By this, he meant that the community believed his father was a witch who was responsible for his son's epilepsy. Similarly, Munya said, 'people used to say a lot of things, like my father had evil spirits or *chikwambo*'. As already described earlier, chikwambo refers to an evil or mischievous spirit; a playful or malicious elf; a frightful phantom; or a gnome. People regarded the act of acquiring a *chikwambo* as witchcraft and believed that the ancestors or God would punish those who acquired riches in this evil way. Hence, Edson's 'disease' was a form of punishment from God or the ancestors for his father's *chikwambo*. Edson said:

> We work with people from different backgrounds … They do not understand conditions like these. They think epilepsy is a curse, a form of punishment from God for previous sins in the family but, I don't believe this.

Edson and Munya said many would not employ people with epilepsy because they believed they were disabled or mentally ill, violent, unstable, incompetent, and were too embarrassed to associate with them. Employers saw them as a risk or liability believing they could not operate machinery, or work with figures.

*Social reactions*

Responses from participants showed that most people in the community, including family members, had reacted negatively to their epilepsy. They had encountered disbelief, rejection, fear, isolation, stigma, doubt, secretiveness, and, in some instances, overprotection. Most families wanted to keep it a secret. Thus, when Saru and Fari found that other people had epilepsy, they experienced a sense of relief and said speaking with service providers at the ESF about their condition had brought healing. For example, Thandiwe reported that her husband's family had expressed disbelief and kept her epilepsy a secret, while her husband took a long time to accept her condition:

> Knowing my epilepsy status gave me some problems, problems I did not face before. I accepted the condition but I realised *my husband did not accept* [it]. He would tell me that 'with that disease no one will love you even your family members'. He even said he will not tell his family members about my sickness. He was always angry about it. So, I think when society looks at this disease, they see it as *a fearsome thing* not acceptable in the family. So, I realised that my husband, meant that this disease *was not acceptable* to the extent that if a boyfriend discovers that you have epilepsy, you will not get married (emphasis added).

Thandiwe had developed epilepsy later in life, when she was already married. Her husband, who had cared for her during the onset of her epilepsy, complained that it was a burden, while she had reduced her participation in social activities. Mambe, Munya, and Agnel talked about feeling socially isolated and feared by others. Agnel said people feared her because 'epilepsy is something people don't understand; our society is unable to treat it and it is something *no one wants to associate with*' (emphasis added). Saru, too, had become socially isolated:

At times, I would not walk alone because of seizures [so] I would not go to parties. At times, I would attend functions briefly and go back home because of fear of seizures.

The words 'fear' and 'doubt' were used by participants often to describe the way their families, friends, classmates, workmates and other members of society reacted when they know that someone has epilepsy or when they witnessed a seizure. The word 'stigma' was used frequently to describe reactions. Words like 'exclusion', 'secret' and incapable' were used, though less frequently. For example, Tonde felt excluded by his friends:

Some [friends and relatives] do not want their children to get near you. They think epilepsy will be transmitted. So, it's hard for managers to accept people with epilepsy. Maybe [it is better] when there is someone you know at the workplace.

Mberi talked about the isolating stigma because people thought his epilepsy was contagious:

Then there is also stigma. If you develop this problem, co-workers will run away from you. They believe epilepsy can be transmitted through saliva. Once you disclose, they treat you as a person with an odour.

Mambe and Munya said that seizures in public places, such as bus terminals, markets, or on the streets, were a nightmare, as onlookers would not help or apply first aid lest they catch the 'disease of evil spirits'. Mambe said, 'I used to fall even at bus stops and people used to leave me alone, they would just ignore me and stay away'. In most cases, she had missed the bus to work and failed to report for work on several occasions. Munya said people from his neighbourhood saw him having seizures in the city centre and, on several occasions, had acted as though they did not know him.

Participants reported varying reactions from their families. Farai and Ashley reported that their families and community had lowered their expectations of them due to their epilepsy,

while Munya felt his family overprotected him. Edson and Masiziba reported that they had supportive families.

*Treatment practices*

Participants talked about the arduous processes they had been through to manage their seizures. For most participants (n=26), treatment started with traditional approaches, including interventions by family members, prophets, church members, or herbalists. Treatment comprised *Chivanhu* and Christian methods, as shown in Table 7.7.

**Table 7.7: Forms of traditional treatment**

| Providers of treatment | Forms of traditional treatment | |
|---|---|---|
| | *Chivanhu* **(African Traditional Religion)** | *ChiKirisitu* **(Christianity)** |
| Self or family members | Ancestral prayer *(kupira mudzimu)* or faith in God and ancestors. | Faith in God/Jesus Christ, prayer and fasting *(kutenda, munamato nekutsanya).* |
| Spiritual mediums or intermediaries | Spiritualists *(svikiro)* or elders. | Prophets, pastors or church elders *(maporofita, mafundisi nevakuru vedzisvondo).* |
| Healers | Herbalists or witch hunters *(n'angas or sangoma).* | Prophets or miracle workers. |

Twelve used *Chivanhu* treatments, 14 Christian methods, and 10 both indigenous and Christian methods, while four had not used any traditional treatments. *Chivanhu* methods involved mediums, psychic readings, clairvoyance, telepathy, divining, soothsaying, and prophecy. Christian methods involved faith healing. Agnel had first received church-based treatments: 'I tried everything, going to several places', seeking traditional treatments as follows:

First my husband, a [name of church removed] church reverend, prayed for me for [several] days. He gave me white clothes to wear and holy water to drink. When this

did not end [seizures], we went to other members of the church. These were more senior prophets, but nothing helped. They recommended more fasting and prayer and an all-night prayer at our home. My husband brought a prophet from another church who said the problem of seizures was coming from my paternal family. The seizures continued and I think I was mad at that time.

Agnel's husband had then taken her to her parents, who suggested *Chivanhu* methods. She described her treatment experience at the hands of her parents as follows:

First, family elders offered treatment with herbs and ancestral prayers… they took me to another prophet who also doubled as a traditional healer in a neighbouring chief's area. They then took me to several *n'angas*, some as far as neighbouring Mozambique [a neighbouring country 200 kilometres away]. When this failed, they took me back home and prepared a ceremonial brew, where a cow was killed and the meat was eaten without salt. Most senior members of the extended family were present. Again, nothing worked.

The failure of church and traditional treatments resulted in people mixing the two methods. Agnel said her parents had used both treatments but to no avail. She recounted how one of the prophets had destroyed the witch's paraphernalia at their home, which included calabashes or gourds filled with blood and covered in colorful beards.

Several other participants had used mixed treatments. Gab and Kocho had undergone ritual cleansing in their homes and had visited spiritualists for cleansing, as these were the usual cultural practices in their communities. Gab had also used herbal tea prescribed by prophets at his church. Nyari recounted how her family had arranged traditional treatment for her to deal with 'the witchcraft' saying, 'we went to prophets. They lied to us as they always do'. As Nyari's was not involved in making her treatment decisions.

Nyari's family had wasted significant resources pursuing ineffective traditional treatments: 'We went to a traditional healer and paid cattle'. Despite this exorbitant fee, it had not worked. Grace had contributed a cow worth USD400, as one of several fees her family had paid for her to see a traditional healer.

Participants pursued dietary regimes as part of traditional treatments, e.g., Lameck had to avoid certain foods, wear a piece of cloth around his waist, and burn incense (herbs) to breathe the fumes or immerse herbs in hot water and inhale the vapour under a blanket. Mambe talked about not eating beans.

Mambe had undergone ritual cleansing for 'bad luck'. Mucha said an *n'anga* had cleansed her and she had 'stayed for some time without seizures' but they had returned. Saru and her family had travelled long distances for traditional treatments. Derry and his family believed he was possessed by evil spirits, so they 'tried everything' to stop his seizures. Even his employer, and friends in Botswana and South Africa, where he had worked, 'just believed it was caused by evil spirits and needed prophets'. Munya sought traditional treatment convinced he was bewitched: We 'saw this old man in Mhondoro who gave us some concoctions. It stopped for about a month and the seizures started again'.

When asked about the benefits of traditional remedies, participants said they were cheaper, readily available, better understood, and, as Mucha said, 'that is the way it is done'. However, Derry said, 'I was affected by epilepsy when I did not know about [medical] treatment … Wish I had known early enough'. Most participants had similar regrets. All received medical services, as discussed in a later section. Saru explained that medical treatment was not well known and not well appreciated. It was a last resort, or an alternative to traditional treatment. Referring to her first traditional treatment experience, she said, 'I did not know about [medical] treatment. I used to try everything'. She had tried faith healing, herbal treatments, and traditional cleansing. Munya and Saru recounted that they had wasted considerable time

seeking cultural and religious solutions. They had experienced delayed medical treatment as an obstacle, resulting in continued seizures that had a negative impact on their skills development, job-seeking, and work opportunities.

### *Experiences and factors relating to gaining work skills*

Participants experienced disruptions to their education at the primary, secondary, and tertiary levels.

#### *Primary and secondary education*

Simbi recounted her days at secondary school: 'It was hard I tell you. People thought I had a condition they could catch. I had no friends. I had to withdraw from the school'. Simbi said her headmistress had asked her parents to take her away from school. She was transferred to another school with poorer educational facilities. Similarly, Grace said:

> Epilepsy started in 1984 when I was at boarding school, [school name removed]. *I stopped going to school … I did not go back to boarding school*. I went to a local school but God helped me, I passed (emphasis added).

This meant that she had withdrawn temporarily from school but had later continued, though at a school with poorer facilities. There was a possibility that parents doubted their child's capacity to progress at school due to a lack of educational support. Hence, most participants reported limited educational opportunities. Participants Gari and Kocho had dropped out of primary school, while Rune, Tonde, Grace, and Simbi had stopped attending school temporarily, changed schools or reduced their school attendance. Rune and Simbi said their families had not done much to support their secondary school education. Rune said:

I went up to Ordinary Level [year four of secondary education], [but] I did not write all subjects [he wanted to be examined in eight subjects but only five were examined]. My parents and community thought I could not proceed with school.

Rune meant that he sat for fewer subjects than he wanted to at the national examinations in his final year at secondary school because he could not pay the fees required by the Zimbabwe School Examinations Council (ZIMSEC) that ran public examinations. Rune, Grace and Simbi's experiences showed that some families had not fully supported the education of their children believing they would not be accepted at school and they needed to be closer to them to manage their situation.

*Tertiary education and training*

Participants Grace, Farai, and Lameck had extremely challenging experiences in tertiary education. Prior to her nurse-aid training, Grace had wanted to be a teacher but several colleges had rejected her application. She had once attempted to bribe an official. She had tried to do a course at a training college run by the Ministry of Health, and had even been prepared to do a rehabilitation course but had 'exceeded their cut off of 35 years'. Asked why she had not enrolled at the college, Grace said it had not recognised her ordinary level passes as she had sat three examinations before succeeding. Like most participants in the study, Grace believed she deserved a chance. Had it not been for interruptions to her education, she would have obtained stronger passes the first time she took the examination. Farai said, after failing his secondary school examinations, he had decided to do an upholstery course. However, he had dropped out after only six months because his parents could not afford the fees and he found it difficult to get to the training venue because of his seizures. Farai was not comfortable sharing his experiences during the six months that he did an upholstery course, perhaps because he had psychological scars from that exercise.

Milton's challenges had more to do with the unavailability of resources than with professional help; he could have done better. Milton had wanted a tertiary qualification to get a government job as a psychiatric nurse or, if this failed, as a teacher or fitter and turner. His biggest problem was 'getting a place' at nursing training college. He had passed his secondary school examinations for entry into nursing college but was unable to 'get a place to train as a nurse'. He thought this was because too many people were applying to do the government-funded free nursing course yet his passes were not too strong. As to teaching, he said his family 'had no money for training', since teachers training college charged 'a lot of money for the training', likewise fitting and turning. Asked what form of family support would have been available had he enrolled for a teaching or fitting and turning course, he replied that there would be 'no support' as his parents were dead and his extended family could not help. Also, he had not been aware of any government-funded opportunities. In any way, Milton doubted whether he would have received support had there been funding opportunities in government because of a lack of social contacts in government. He said, if he had got a job, he could have paid his own college fees. When asked about his plans, Milton said he was already looking for work positions in New Zealand and USA despite his unskilled worker status.

Simbi had enrolled in an accounting course but had withdrawn because she was having frequent seizures, was not working and could not afford the fees. Her parents had been unable to support her in the absence of a government training initiative. Before the accounting course, she had wanted to be a nurse or a teacher but like Milton and Grace, she did not get a college place because her passes were not too strong. She attended two interviews at different colleges, but failed. On the second occasion, she had a seizure just before the interview, she proceeded but she was not in a good mood to pass the interview. Later, she had supported herself through her university degree.

Other participants had had challenges getting work-related learning, a key component of tertiary education. Grace's employer had dismissed her in the middle of her internship after she had had a seizure at work. Munya had had three seizures during his three-month internship and the employer was not pleased. A lack of vocational education meant participants like Rune were unqualified or had not qualified as quickly as their peers. They all lacked adequate support from their families and from the government for vocational education. Vignette 7.1 describes Rune's challenges in living with epilepsy.

**Vignette 7.1: Rune's experience of living with epilepsy**

By the time of the study, Rune was 29 years old. His epilepsy had started when he was a child but was still only partially controlled. He was getting medicines from government hospitals and from the ESF. He said traditional interventions were very helpful, although he had to rely on medical treatment himself. He finished primary school but did not finish secondary school because his family thought he would not pass, so they did not pay his school fees. He did not do any training and never looked for a formal job. He did household chores or piece jobs for neighbours but they paid very little money. He said there were better paying informal jobs, such as construction, but even his old schoolmates with such opportunities had not invited him to join their networks. He said he was very good at mathematics and, at times, he had worked as a shopkeeper at a relative's market without pay. He hoped to start his own market but had no capital and there was no one to loan him the money he needed.

## *Experiences and factors relating to job seeking*

Job seeking was challenging for most participants due to a number of factors, including weak social networks, limited family and relational support, and employment services, limited welfare and disability services, and a challenging economic environment, as discussed below.

139

*Poor social networks*

Negative attitudes, such as fear and doubt from peers, family members, and relatives associated with epilepsy resulted in limited social interaction and social networks for some people with epilepsy, like Rune:

> I was with them at school [his peers]. Now they have some jobs like building and others. They look at me and say that this person is sick. They do not know that I can do the type of jobs they do. *They think I am a sick person*. They do not ask me to join them. I wish I could join them so that I get income (emphasis added).

Unlike others his age in their neighborhood, Rune could not find work, as he was outside essential networks. Vignette 7.1 presented earlier, provided more information about Rune's experiences.

Edson's sister had helped him secure employment: 'I don't have ordinary level [secondary school] passes. I did not do any course, but my sister helped me find a job'. This was his only job. Farai and Rune said their families did not think they could find jobs and work productively. Tindo and Nyari's husbands did not allow them to work. Nyari said, 'from 2003 to 2005 I was married and I was not allowed to work or do any business by my husband'. However, Nyari's brother had assisted her with applications and informing her of available job opportunities.

Participants reported difficulties finding employment when people knew they had epilepsy. Masiziba said she was 'doubted' when she applied for a job as a cook. Rune had had a similar experience. Masiziba, who was still unemployed, observed that:

> Employers should not judge me because they don't know what I am capable of doing. If I applied to be a cook, I will prove them wrong by cooking a meal they will never forget, a delicious one.

## *Absence of employment services*

No participant received government employment services, although there was a public agency responsible for such services. They pointed out that they had not known about the service and doubted whether they would have received an adequate disability-friendly employment services if they had approached the agency. However, Grace spoke glowingly about the social work services she had received at a government-supported rehabilitation centre near Harare:

> I was looking for work. I also went to Ruwa Rehabilitation Centre for training in secretarial work. But they told me that I was qualified and I should go and see the Disability Board to help me get employment. I went to see them at Ministry of Health … They gave me a letter to see Dr [name removed]. Then referred me to Mrs [name removed] and Mrs [name removed] in the Ministry of Health. I wanted to get a place to train as a nurse not to do sewing offered at Ruwa … I can say those at ESF helped me with letters. At Ministry of Health they would say go and ask Harare hospital for a job. I worked there 2000-2001 but I left after the contract ended … At Ruwa, the social worker insisted that I should see Mrs [name removed] who was in the Disability Board.

Ultimately, Grace secured employment at the country's biggest hospital as a care assistant with the help of senior officials in the Ministry of Health. Nevertheles, as shown previously, Grace failed to secure a place for tertiary education to become a skilled worker.

Tindo and Hadeel had relied on nongovernment organisations, such as ESF, but had not received adequate employment services. Hadeel talked about how ESF had helped build her self-esteem. She attributed her improved job-seeking skills and self-belief to the organisation:

> What I can say is I got support as a person with epilepsy from the ESF, somehow it groomed me and ... and still it made me aware that I can still compete in the employment sector even if I had epilepsy.

Gari had received employment support services from the Leonard Cheshire organisation, including training in art and referral to an art organisation for internship. The organisation had been unable to secure a permanent job for him and its employment services had been shortlived. As shown in the previous section, Milton and Simbi did not get these services and Simbi did not perform well during interviews. Further, Milton had hopes of working in New Zealand or USA but he lacked the skills and finances to achieve that, hence employment support services, such as career guidance, were more than wanted.

*Limited access to welfare and disability services*

Participants reported that they had limited access to public welfare and disability services that would assist them reduce barriers to employment. They pointed to the government's failure to implement disability policies that would provide access to disability grants and jobs. They lamented the lack of government assistance and social support. Tonde's had to miss primary school for days because his grandfather, a driver, could not afford the fees. He had also not received help from the government programs for orphans. A nongovernment organisation, Plan International, had supported his primary and secondary education. None of the participants had received a government grant, although the government provided a means-tested grant of USD20 per month to other people with disabilities. Lameck and Mucha said it was because government officials did not consider epilepsy a disability. Mucha believed that 'epilepsy should be considered as a disability and people with epilepsy should also get government grants'. Lameck said the lack of a support grant to people with epilepsy was a form of discrimination that happened because officials thought epilepsy was a spiritual condition, and not a disability or medical condition.

While financial support was not available from government, Rune, Gab, and Ashley were getting free tablets each month from public clinics though Gab and Ashley insisted the government was not doing enough and, at times, there were no drugs at hospital dispensaries.

The public clinics provided free anti-epilepsy medicines to people with epilepsy as part of government support for people with psychiatric conditions since epilepsy was clustered under psychiatric conditions.

*Economic environment*

Zimbabwe's struggling economy was a major feature of participants' experiences. Hadeel reported that there were few jobs available on the open labour market, because some companies had closed as the economy continued to weaken. Private sector companies were retrenching workers or failing to pay their salaries on time. Tonde said it was useless to keep looking for work because 'the companies are not taking anymore. They are retrenching. You need to know someone [to get a job]'. However, some industries were still running, and the public service had increased its size significantly. The informal sector was growing, and many more people were finding work there. Further, migration to neighbouring and distant countries provided millions of Zimbabweans with jobs. The increase of the public service, the growing informal sector, and possibilities for migration gave people with epilepsy hope that they would also find jobs. Participants preferred jobs in the government service, but they were difficult to come by because their qualifications were not competitive. However, a weak economy made competition harder in the private sector. The absence of employment support services disadvantaged participants. As a result, Hadeel sought employment in a neighboring country. Problems in the economy pushed participants into unproductive work or work they were overqualified for because no other options were available to them. Nyari, who had a diploma, accepted low pay at one of her jobs 'because of the economy; it was hard to get jobs so I saw it as a miracle to have been offered a job. So, I took the job'. Simbi was a part-time employee though she said 'I [would] prefer a government job because it is more secure. They [the government] follow labour procedures to "fire" employees'. Bilaal worked in the informal sector, which did not pay much. He survived on selling used printer cartridges.

Despite the challenges already highlighted, some participants were able to get jobs. However, most could not work productively or maintain the jobs because of the employment challenges they had encountered, as shown in the next section.

### *Experiences and factors relating to the workplace*

Participants reported challenging workplace environments, including negative attitudes from employers and co-workers, limited on-the-job support, and job loss, while some women were overwhelmed, as discussed in turn.

### *Attitudes of managers*

Edson reported that he could not take his medicines in the workplace because he had not disclosed his condition for fear of losing his job, because he was 'mentally ill'. Because Edson had not disclosed his condition, preferring to report 'frequent headaches and rheumatoid arthritis' instead, he could not easily get time to visit a doctor or take longer breaks when needed, as his manager saw this as loss of work time.

When asked whether they had told their employers, prospective employers or co-workers about their condition, most said they had not disclosed, some had partially disclosed, and only two had fully disclosed. Thandiwe, Rugare, and Edson discouraged disclosure because their jobs were precarious; they were afraid of dismissal once discovered. Thandiwe said her job hung by a thread: 'I am afraid if I tell them [employer] they will then say I will pass on the disease to pupils. So, I don't know whom to tell exactly'. Employers and co-workers reacted differently when they knew about their employer or prospective employer's condition. Participants said people treated them unfairly once they disclosed their epilepsy. While Edson had not disclosed his condition to his employer, Lameck and Munya had but their employers had not supported them, since they viewed epilepsy as a spiritual rather than a health condition. They had not allowed Lameck time to seek treatment, while they had dismissed Munya for

spending a lot of time off work. This was unjust, as other workers easily got sick leave. The employer had transferred Lameck from department to department and had not given him responsibilities at the factory where he worked 'because they thought I would die at work'. Edson said he was 'not taken seriously at work' and, at times, employers had brushed off Lameck in favour of 'the next guy'. Lameck said:

> I think the way they took it they did not have full knowledge. They were not informed. *Management was saying I could die at work or have another seizure.* I would feel the segregation when duties were shared but I could feel that I could do this and that. The doctor said if you are taking drugs, you can go back to your normal work. They had a nurse there and I explained and she said it was ok but they kept on postponing until the six months' contract expired they would not renew it. I think they wanted to cut the contract short but they then just waited for months to end and failed to renew my contract. I kept pestering them to return me to my duties (emphasis added).

Tonde, Mberi, and Tindo reported, too, that their managers feared they would die at work or scare off customers. Tonde said his employer started 'complaining that it's risky for you to work here'. Mberi said employers 'treat us as lepers'. Simbi said her employers 'were afraid I could get their money stolen. They also said I could scare customers away. They did not provide me with an alternative'. Simbi, who worked as a till operator in a retail shop, had similar experiences.

Tindo and Rufu said their employer underpaid them because of their condition. Tindo said, 'my employer thought she could pay me less since she employed me because I had epilepsy, she felt like she was doing me a favour'. Tindo's employer had taken advantage of her vulnerability. She could not afford a lawyer to help her file a labour case for unfair pay. Vignette 7.2 describes Tindo's employment experiences.

**Vignette 7.2: Tindo's employment experiences**

Tindo was 33 years old by the time of the study. Epilepsy started when she was already a young adult. She had completed her secondary education but had not passed all the subjects required to proceed to high school or college. Her family pursued traditional treatments. Tindo and her family faced negative attitudes, such as stigma from the community. She looked for work but could not get it. She acquired a diploma but she still could not get a job. She got a job in a retail shop. The owner knew about her condition of epilepsy but was willing to hire her but she was underpaid, despite having been dependable. She thought this would improve but did not. She approached the employer who indicated to her that she hired her because of her condition and that no one would hire her. Frustrated, she resigned. Another company hired her. She believed she was hired because she had been seen working at the previous employer and her work was impressive. Sadly, this new company folded and went out of business. She was jobless again. By the time of the study, Tindo had enrolled for another diploma program at a local college.

*Attitudes of co-workers*

Asked what this meant, Edson said they were saying he was 'mad' and there not capable because he had occasionally experienced 'blackouts' at work. Edson reported that co-workers doubted his capacity, and they disagreed with management's decision to name him worker of the month. He recounted how his colleagues had not been pleased with the company for giving him an award, referring to him as a SASCAM, a connotation derived from a mental health organisation that once provided services to the mentally challenged in Zimbabwe. Edson described bullying from co-workers who made constant jokes about him being 'mad' or being a SASCAM.

In discussing his employment experience at the hospital where he worked and the way in which fellow employees and patients had treated him knowing he had epilepsy, Ishmael

recalled that while 'some took me as a normal person, some did not care and some maintained a distance from me'. When questioned about what he meant by 'maintaining a distance', he replied, 'they were afraid' and 'did not want to be bothered … They were afraid to work near me. Some of them did not have knowledge about epilepsy'. Tindo spoke of the attitude of her co-workers:

> The problems were that some of the people I worked with did not understand me…The environment was not conducive like you will be working under pressure. Pressure triggers seizures and some of the co-workers would trigger my seizures deliberately because they would have seen that as my weakness.

Munya felt mistrusted by workmates. He shared his experience, taking time to finish the statement, with breaks in between, perhaps because of the emotional nature of the experience he was recalling:

> So, in terms of employment I must confess, it's very difficult. People do not say it, but you can feel it. There is kind of mistrust (*silence*). It is the negativity of epilepsy being associated with mental illness. Epilepsy is a mental condition, but not a mental illness. If I forget a file, it's always 'because he has epilepsy but everyone forgets'. At [name of employer removed], it was torture, it was torture … (*silence*).

For him, the mistrust persisted even when he had obtained a driving licence; the employer initially would not let him drive company vehicles. This continued even after he had gained driving experience. When he started getting cars to drive at work, co-workers did not want to travel with him. Asked to explain the driving requirements for people with epilepsy, Munya said the testing office had told him that he needed to have been seizure free for two years and this had to be supported by a doctor's letter.

## *On-the-job support and adjustment*

During seizures at work, first-aid help was not always forthcoming; instead 'those around would run away', recounts Mambe and Mucha. Their accounts were the same. They said that those who ran away were afraid of their seizures. Some believed they would get epilepsy through saliva or puff or the spirit could move to grab the nearest person. Mucha, who was a teacher, recounted how schoolchildren would jump out of windows each time she had a seizure. Parents withdrew their children from the school where she was teaching for fear that their children would contract epilepsy and because they doubted her capacity to teach their children. In exploring her employment experiences, she recounted:

> The headmaster and teachers understood but the parents and students were not understanding … They would say epilepsy is contagious. Other parents had to transfer their kids. They said their kids would get epilepsy … They would not switch classes, so they would change kids from our school.

Mucha said at college, her lecturers and college mates had accepted her, 'maybe because I started college without [epilepsy]'. However, the transfers worried her. She recounted what happened one day at her new school:

> I then realised that teaching seven classes was a challenge. I had piles of books to mark at the end of each day. I then transferred to [name of school removed]. I had a seizure one day but the headmaster did not allow me to go home. I thought if I went back home I would sleep it over after taking medicines, actually an overdose. She said I should write letters for leave. I explained I was expecting other seizures and would not want to have seizures in front of kids. The absence seizures are very funny. At times, I walk around, stare strangely and I think this would have confused kids. So, the head said I think you will have problems but she could not say more. I told her I will manage my

class. I am able to manage it but she was saying we just keep an eye on you because if you keep disturbing the school with seizures we will act upon it but they did not tell me how they will.

Absence seizures could be like 'blackouts', 'blank spells', or 'absent mindedness' in some situations. This was what Mucha experienced in class, and what the children feared. The headmaster had not used the time it took for her to recover from a seizure as an opportunity for the students to learn from the experience.

Relatively few participants had gained formal employment that enabled them to pay income tax and to contribute to government's compulsory social security scheme.

## *Job dismissals*

Hadeel, Saru, Munya, and Tindo had the highest number of jobs (n=4), Thandiwe, Simbi, and Derry had three, while the remainder had up to two jobs, with nine never having been formally employed, as shown in Table 7.8.

**Table 7.8: Number of employers**

| No. of employers | No. of participants | Names of participants |
|---|---|---|
| 4 | 4 | Hadeel, Saru, Munya, and Tindo. |
| 3 | 3 | Thandiwe, Simbi, and Derry. |
| 2 | 8 | Mucha, Ashley, Grace, Lameck, Ishamael, Zoey, Mberi, and Tonde. |
| 1 | 6 | Rugare, Rufu, Edson, Farai, Nyari, and Mambe. |
| 0 | 9 | Masiziba, Agnel, Milton, Gari, Sanga, Rune, Kocho, Bilaal, and Gab. |

Instances of job loss were very common through dismissal; there were 16 instances of dismissal among the participants. Participants gave several reasons for dismissal. Simbi had had seizures at work; Tonde was alleged to have been sleeping at work; Lameck had been

accused of being drunk at work; and Simbi had been dismissed as 'a bad omen'. His employer believed they would lose customers when someone discovered that there was a person with epilepsy at the company. Tindo's company had dismissed her, along with many others, because it had run out of resources. In recounting his first dismissal, Munya said:

> [In] 2010 I was unemployed. I was very sick. I tried to take my degree anywhere I could but [I got] no job. I [later] got a job with the [government water company], I worked there … I was doing public relations. I had two seizures while on probation. I did not get the job because of seizures. Obviously, they did not tell me that. They said we feel you did not meet our expectations but I felt I had done a good job under the circumstances. I had organized World Water Day at Great Zimbabwe, everything going on well. Unfortunately, I did not get the job and I had always believed it was because of epilepsy.

Although Munya had been on probation, he felt their failure to keep him on was due to his epilepsy, and having had two seizures at work. He believed he would have got the job had he not had any seizures. He also talked about having worked well for those three months and also that it was rare for public entities to have employees who failed probation. For the second dismissal, he said:

> I have had nasty experiences. I once had a seizure at Gutsai supermarket. I was coming from the bank after banking. I had bank slips. I did not have any cash. I was coming from the bank around 3 or 4pm. After the seizure, I woke up to see a lot of familiar faces because I live in Kuwadzana and that area has a lot of people passing from Kuwadzana. When I gained consciousness, I saw bank papers and I thought I was going to the bank. I found it closed and sat in front. One lady, who worked in the same office with me, saw me and did not do anything but just went and told security. They sent

someone to look for me. I fully regained consciousness and realized I was very dirty. I started moving to the office and they took me to Parirenyatwa [a hospital]. *They said take some painkillers and go back home.* That did not help my case, they eventually get rid of me. It happened once but it did not help my case as well. Employers need someone working, not getting lost (emphasis added).

Grace, who was on three months' work training as a nurse aid at an aged-care facility, had had a seizure 'when I was rubbing medicine on the back of a patient'. They had dismissed her because she did 'not qualify to work at their place and at Ministry of Health as a nurse aid'. She had only worked there for two months. Speaking slowly, she said she had been 'affected a lot but there was nothing to do'.

Saru said she had an attack while teaching and was dismissed from work:

In 2011, I got work at [name of school removed] but they dismissed me because of epilepsy. It was a private school. I worked for 1 term and they just paid me and let me go. Maybe because it was a private college. I just accepted it as it was … I had an attack in front of the pupils. They then said my contract will end at end of month. I just accepted it. I had come to a situation where I even prayed behind my house that God should end my life. At times, I would not walk alone because of seizures. At times, I would not go to parties. At times, I would attend functions briefly and go back home because of fear of seizures … I also had memory problems.

Similarly, Simbi said she had worked for a supermarket at the till but one day had had a seizure during work. Customers, co-workers, and managers looked at her with surprise and fear. Some customers had moved away without offering help. Although the manager had felt sorry for her, the company had fired her for not disclosing her epilepsy. Asked why, Simbi said

'honestly, if I had told them, I was not even going to get a job there. I worked for another company it was the same'.

Mberi said he had not disclosed but his employer had dismissed him nevertheless. Mberi believed his 'bosses' had observed that he had a 'disease' and had decided to dismiss him. Asked why he believed this, Mberi said the employer had dismissed people with other medical conditions, such as diabetes, work injuries, who were 'generally weak'. Mberi said his medication made him weak and, at times, he would feel sleepy at work.

*Gender roles*

Hadeel, Simbi, Ashley, Mucha and Thandiwe drew attention to factors affecting women in the workplace. Hadeel said:

> I'm very much interested advocating the rights of people with disability, especially women with epilepsy. I am a very staunch advocate in that line of work, especially to see women with disabilities, particularly with epilepsy not being stigmatised and discriminated upon. There is really need as women with epilepsy to make people understand and realise that what we have is just a condition that can be controlled and one can live a productive and happy life as well.

Simbi, Ashley, Mucha, and Thandiwe said they had felt overwhelmed with work. Mucha said being a female worker, wife, and person with a chronic condition was:

> the boring aspect of epilepsy, especially for women like myself, is that after work you need to work at home again. You then need to sleep early and prepare for work again. At times, I feel like I should start my own company and control my timetable.

However, Mucha had received support from her husband and this kept her roles manageable at times. 'Actually, I want to thank my husband' she said adding that her husband was supportive

and understanding. Asked to explain, she said her husband supported her with household chores and allowed her to hire domestic workers when she felt overwhelmed. Her doctor had recommended a drug that was not available in Zimbabwe, hence her seizures were not fully controlled.

Thandiwe had problems with her husband accepting her condition that intensified when she fell pregnant as the seizures had increased. It became difficult for her to balance home, work, and health:

> Yes, I got stressed. Sometimes the seizures were too much especially when I was pregnant. My husband would label me saying I was sick because of spirits from my family. At one point, my husband said your relatives did not tell me you are sick. But I think my family did not know about it. My father tried everything to ensure I was well but the problem was not that big that it warranted him to inform my husband when we were about to get married.

Regarding the challenges for women with epilepsy, Ashley said, 'on top of that I then fell pregnant and it became too worse I tell you. I also had work to deal with'. Later, she had left work.

## *Experiences and factors relating to support services*

Participants reported challenges in securing supportive employment, disability, and welfare services. This extended to public services supporting small business development, as well as health, legal, and nongovernment services.

### *Informal sector and small business services*

Nyari and Gari ran small businesses in the informal sector, where they faced numerous challenges without support from the government Ministry of Small and Medium Scale

Enterprises, as they did not qualify for its services. The Department of Social Services offered disability grants to groups running income-generating projects but the cumbersome application process made the prospects of accessing this support extremely slim. The government and municipal police had harassed Nyari, a roadside vendor in Harare. Gari, a trained shoemaker, could not make shoes without a machine, thus his dream of starting a small business had not materialised. Resultantly, their income in informal employment was so meagre that they did not consider themselves employed. Ashley was an exception. She had started a retail manufacturing wholesale business following her retrenchment, which had succeeded and earned her business awards. With the support of her family, her enterprise grew from a small to medium business.

## *Health services*

All participants received medical treatment following a clinical diagnosis involving an electroencephalogram (EEG) and counselling to increase treatment compliance once on anti-epilepsy medication, with one exception. Each had experienced varying degrees of seizure control that had affected their employment status.

Most of the participants had not received the high-quality specialist care needed to address the complications in their treatment, as shown in Table 7.9. Most participants had received first and second-line treatment. First-line was basic treatment offered at primary healthcare centres, while second-line treatment was available at a few centres in the country, including the ESF. Few had received third or fourth-line services. For example, Mucha complained that although she had been prescribed third-line medicines, these had not been available and were not on the government list of essential medicines. With the assistance of relatives who worked outside Zimbabwe, she had been able to procure these expensive medicines. One of the participants had been assessed for, and undergone surgery, but none had

been assessed for or placed on a ketogenic diet, recommended for patients who failed to respond to medication.

**Table 7.9: Forms of medical treatment and diagnosis**

| Level of medical treatment | Description | No. of participants treated at this level at least once |
|---|---|---|
| Primary (First-line) | Clinical diagnosis | 30 |
| | First-line medicines | 29 |
| | Primary healthcare services | 30 |
| Secondary (Second-line) | EEG | 30 |
| | Second-line medicines | 11 |
| Tertiary (Third-line) | MRI or CT Scan | 6 |
| | Specialist physician | 11 |
| | Blood serum level tests (toxicology) | 4 |
| | Third-line medicines | 4 |
| Quaternary (Fourth-line) | Surgery | 1 |
| | Ketogenic diet | 0 |

The medical services available to participants did not always succeed in reducing or ending seizures. Lameck said, luckily, his first medical treatment had stopped his seizures, but Rufu, Saru and Farai continued to have seizures while on medication. Rufu had started treatment soon after his first seizure due to the immediate attention of a nurse in a nearby public clinic. Lameck had obtained speedy medical treatment at a clinic in his workplace. However, Saru had delayed treatment, focusing first on traditional interventions. Though Farai was on medical treatment, his seizures continued:

> I have partial seizures, sometimes [an] absence [of] seizures. The whole body is affected. I fit terribly. I comply with treatment, I had several EEG and CT scans, but I am not controlled since I was a child … Currently my seizures are getting more because of the weather. If it gets sunny, I get headaches and start fits.

Farai thought he needed to see a specialist but there was no neurologist available in the country.

There was inadequate post-treatment support to help participants comply with treatment. Agnel had started on traditional treatment and switched to medical treatment briefly before going back to a traditional healer:

> At the nearby [about 10 kilometres away] clinic, I was given phenobarbitone which I only took for a few weeks and stopped. There was no change, in fact it looked as if the seizures had been ignited. We went back to prophets … After about six years, one of my cousins convinced my parents to take me for treatment in the city. I saw a specialist who did an EEG and I was put on carbamazepine. Since then, I never had a seizure. I could have been withdrawn from medicines, but there was no longer a specialist to assess me and recommend that. So, I still take a tablet a day.

Initially, Saru had been treated at a public clinic, where she did not receive a very good service. Had she received aftercare services, she might have complied with medical treatment. Her experience reflected her initial lack of awareness that epilepsy was a medical condition easily controlled with medication. Saru recalled:

> In 2011, I came to ESF and I got hope. It was after someone who works at [the] post office saw me lying on the ground. I then went to ESF and got help. After my first treatment there, I never had an attack. Last time I asked the doctor if I should keep taking medication, he advised me to take medication for five years and assess after that … I had my first treatment on 11 April 2011 and that was that. I then stopped having seizures until now. I returned to work in 2012 in January. I reapplied to join [the] government. Initially, I had resigned in government to join [the] private sector. I had no epilepsy then. I worked at [name of school removed] from 2003 to 2010. I would at

times have attacks even in front of parents. I was even a teacher in charge. They understood my situation.

Vignette 7.3 discusses Saru's experiences with delayed medical treatment.

**Vignette 7.3: Saru's experience of delayed medical treatment**

By the time of the study, Saru was 39 years old. Her epilepsy started in her thirties, when she was already working. She had had a normal childhood. After secondary school, she trained at a Teachers College and subsequently got a job teaching at a rural school. Later, she transferred to an urban school where she got a much senior position. It was at this school that she stated having seizures. She said the school was supportive all the way until her contract ended due to a lack of funds; she firmly believed it had nothing to do with her condition. She sought work at a private school but only worked for three months, when she was dismissed after having seizures at work. She had not appealed and remained unemployed. She was also not on medical treatment and had tried several traditional interventions without help. All along she was driving, but it became dangerous for her, due to her seizures. She decided not to drive following a seizure in the city centre. The person who assisted her had heard about the ESF so advised her to go there, which she did and was put on medication. Her seizures were instantly controlled. She went back to the public service, where she got a job as a teacher at a public school. Since then, she had been teaching at that school. She was fully controlled and had never disclosed her condition. Now she drives and participates in activities at the ESF.

Some participants encountered poor service delivery at public health institutions and had difficulties accessing these services. Most relied on nongovernment services, mainly the ESF. Munya said he had visited public hospitals several times, but had never been given a proper diagnosis. His aunt had told him about medical treatment at the ESF, whereafter he had sought medical attention there. He described his experience as follows:

For doctors, at times when we get to hospital for treatment there are challenges like long queues, some workers do not understand the condition. If you try to ask them to help you faster, they say you are lying. I think we should have specialized people to help us when we visit hospitals, like the Psychiatric unit … I even went to Harare hospital twice but they never treated epilepsy. They gave me general treatment. One day I fell at the clinic after taking my child there, but they took me to the hospital but they only provided general treatment. They *said take some painkillers and go back home* (emphasis added).

Poor service delivery drove participants to traditional healers. Munya had been given painkillers when one of the biggest hospitals in the country failed to accurately diagnose his epilepsy, consequently, he had received traditional treatment from an 'old man [a traditional healer] in Mhondoro, who gave us some concoctions [herbal treatment]. It [epilepsy] stopped for about a month and the seizures started [again]'. Once on medical treatment, Munya found that, 'at times, [the] side effects were a challenge. Medication controls the condition and not side effects. This is a medical condition, requiring medical treatment' but the side effects of medication could not be controlled adequately. Hence, most participants used a mix of traditional and medical treatment methods.

Farai said he wanted to work as a salesperson at the company where his father and brother worked, but was unemployed due to continued seizures, despite medical treatment. He had been able to get a job as a housekeeper despite 'having so many seizures at work … Currently my seizures are getting more because of the weather. If it gets sunny, I get headaches and start fits'. Farai was not alone, Mambe had stopped work on her own due to continued seizures, while Nyari had stopped work because 'at one period I lost my memory due to severe seizures'. Tonde spoke of his fear of epilepsy and its effects on his work choices: 'I want to be a forklift operator but I am worried epilepsy may affect me. I am still considering. So, I'm

158

looking at seizures and will see how it goes'. Masiziba, who made and sold beads, said she experienced blackouts and was afraid to go out alone. Mambe used to have seizures on her way to work. Edson, who was taking sodium valproate medicine, said he had experienced side effects, such as appearing to be drunk. Yet, without treatment, seizures affected the productivity of people with epilepsy and gave rise to realistic employer concerns relating to a loss of alertness at work, injury, and mistakes.

## *Legal services*

Participants reported that they had not sought public legal services because of the lengthy time it took for their issues to be brought to court. They said public lawyers were overwhelmed with work and often the process to get free public services was cumbersome. Private lawyers were not consulted because they charged exorbitant fees. Participants said some employers had hired lawyers and challenged cases against them, while employees could not afford legal fees to mount a solid defense. Edson suggested that workers with epilepsy should have their own lawyers, a form of legal aid, to help them with legal challenges.

## *Nongovernment services*

In response to the lack of public services, participants had sought the services of nongovernment organisations, mainly at the ESF. Some participants had joined support groups for young people, women, or income generation. ESF staff had visited their workplaces, schools, or homes to promote epilepsy awareness. Participants had also received counselling and support from relatives, church members, and others with epilepsy or other types of diseases or disabilities. Farai, who was employed, despite his uncontrolled seizures, had benefited from ESF's intervention:

> At first my parents did not allow me to visit the support group of young people with
> epilepsy for fear that my condition would be known. They also feared that they would

be called back from work to provide first aid to me or to take me home. So, the social worker at ESF visited our home and spoke with my father. This changed everything.

Saru praised the counselling she had received: 'In 2011, I came to ESF and I got hope'. The counselling and support she had received enabled her to overcome her feelings of loneliness, stress, and suicidal thoughts. In addition, at times, church members had visited her at home to offer their support.

Munya recounted how ESF had helped him. At ESF, he had met other people with epilepsy who shared their experiences. He had contributed his life story to a ESF booklet on experiences with epilepsy. He had also participated in advocacy and awareness meetings. One such meeting was the official opening of National Epilepsy Awareness Week of 2014, where he had shared his testimony.

Participants also talked about the income-generation training and projects they had received with the support of different organisations. These included floor polish making, which they referred to as cobra (a popular brand of floor polish) making, shoe making, sewing, and peanut butter making. They had trained in production and basic management. Some participants had been given start-up equipment and inputs to engage in self-help jobs, while others been funded as groups operating at selected a central location.

## *Experiences and factors relating to self-management*

Although this study focused on structural factors, self-management (or *individual* coping behaviour) emerged as a theme. Participants in this study showed different levels of coping, depending on their personal and environmental circumstances. Richardson's model was used to classify participants as resilient and vulnerable but was adapted into four categories, as shown on Table 7.10, which shows that, on Richardson's scale, employed participants (n=8) scored higher on resilience than unemployed participants (n=22). Of the vulnerable participants

(n=22), 16 were unemployed. Though Table 7.10 does not show gender, four female and four male participants scored high on resilience. The categories were based on the researcher's assessment of each participant's responses. The researcher examined the odds stacked against each participant and evaluated these against their experiences in training, education, employment, treatment, and attitude towards epilepsy. The experiences classified as demonstrating resilience and vulnerability are each presented in turn.

**Table 7.10: Resilient and vulnerable participants**

| Vulnerable | | | Resilient | | |
|---|---|---|---|---|---|
| Mostly | At times | Total | At times | Mostly | Total |
| 0 | 6 | 6 | 2 | 5 | 7 |
| 7 | 9 | 16 | 1 | 0 | 1 |
| 7 | 15 | 22 | 3 | 5 | 8 |

*Resilience*

Despite challenging experiences, some participants had demonstrated their resilience by getting quality treatment, education, and training; adopting a positive attitude; and being self-advocates. For example, mindful of her treatment, Mucha had learnt to control the factors that triggered her seizures. As she explained:

> Get yourself treated, maintain yourself so that you can keep your work. Those not employed, do self-jobs like woodwork, welding, and just do not neglect yourself. Epilepsy is just a condition.

Farai was also cognisant of triggering factors, such as sun heat. Unlike others, Saru, too, had accepted her condition and adhered to medical treatment.

Though Munya already had a university degree, to ensure better chances for promotion at his workplace, he had enrolled in a professional course and obtained a driver's licence, despite the tiresome process. Hadeel and Simbi had recently obtained university degrees, studying while working in the hope this would improve their employment opportunities. Similarly, Lameck and Tindo had enrolled in diploma programs to enhance their employment prospects. Some participants had learnt to stand up for themselves and be their own advocates. Edson said:

> In most cases, I think it starts with you, the person with epilepsy. You should accept your condition and also educate people around you. Know what your condition requires. If you educate someone and they do not understand, ask someone else who knows to further educate them.

Edson and Munya said people with epilepsy had to be role models of positive treatment outcomes and advocates for sound employment policies. Munya noted:

> I told my boss I have epilepsy. That is me. If you ask me to raise a policy [part of his job] I will do that. If you give me any job, I will do it. If I have a seizure in front of a client and you lost business, then I am sorry but that's my situation.

Munya, who, unlike the rest of participants was interviewed at work, had faced several challenges in the past, but thought it best that people with epilepsy challenged society to understand and accommodate people with epilepsy.

Several participants talked about the rewards of hard work, reliability, and dependability. The researcher categorised impressive work performance, despite workplace challenges, as an indicator of resilience. Nyari said people with epilepsy had to prove their value in the workplace to dispel the myth that they were unproductive. They had to build employer confidence by being reliable and independent: 'If they get work, they should work

effectively and deliver results … I am someone who is confident, ambitious, with high self-esteem, and I am patient and hardworking … [and] work with … minimum supervision'. This paid off when Nyari's second employer gave her a job because she realised that Nyari was reliable and could work independently:

> The other issue is I didn't choose [this]. Like for my second job, the employer saw me when I was working for the first and really liked the way I worked. So, when my contract expired after six months, she offered me a job. So, it was just getting the job and taking it. I had nothing to do so I took up the job quickly … Yes, as I alluded earlier, it's the way I do things; I work with perfection and with minimum supervision. When I was at the first job, the second employer realised that I was reliable. The employer would leave me alone but work would move without any problems.

Rugare 'had to work hard to compensate for my weaknesses'. Farai had kept his job for over seven years: 'Maybe because of hardworking and also, if they give me work, I do [it] without questioning, I just do [it]'. Similarly, in Vignette 7.2, Tindo showed that she was a hard worker.

Participants talked about the importance of a positive attitude to overcome employment barriers. Grace said she had moved from office to office, pestering government officials to provide her with a training place or job. Grace finally found a job at one of the government hospitals and, by the time of the study, was still pestering them for training place at a college so she could become a skilled worker. Zoey said people with epilepsy should 'not look down upon themselves' and should seek employment in the same manner as people without epilepsy, who did informal work or sought informal and formal employment outside Zimbabwe, as Munya, Hadeel, and Derry had done. Simbi said she had wondered why other people were getting work, while Mucha said they needed a 'fighting spirit'. Sanga kept a positive attitude despite the challenges he faced:

We have to see ourselves as able-bodied people able to perform. We should see the sky as the limit. We should look at ourselves as normal, fit and strong. My sister used to think I will not achieve in life but here I am, am doing fine.

Munya, whose story is presented in Vignette 7.4, had remained positive.

**Vignette 7.4: Munya's epilepsy dilemma**

Munya started having seizures when he was in his final year of university. The immediate explanation was that he had been bewitched to avoid him graduating. As a result, his family sought traditional interventions. As part of his final year at university, he had to undergo internship. During internship, he encountered the challenges of epilepsy in employment but he finished the internship and graduated. He got a part-time job at the company where he had done his internship, but they dismissed him because of his seizures. He was not on medical treatment. Though people had taken him to hospital several times following seizures, he had only received attention for his injuries and doctors had never properly diagnosed his epilepsy. He got a job at a parastatal (semi-government institution) that placed him on three-month probation. During the period, he had had two seizures at work, resulting in him not getting a permanent position. He said he had been surprised because he had worked exceptionally well. As was the norm in Zimbabwe's weak economy, Munya had gone to a neighbouring country, Namibia, to find work. He had found a job and had worked well, remaining seizure free. However, the job in Namibia required a driver's licence so he had gone back to Zimbabwe, where he had been unable get the licence because he needed to be seizure free for at least two years. He could not go back to Namibia. Luckily, he attended an interview and got a job at a company he had worked for before. In his opinion, the main reason he got the job was that he had shown them that, despite epilepsy, he was hard working and very productive. He sought medical treatment at ESF and his seizures reduced. He applied for his licence, got it, and could drive company vehicles at his new workplace. He became an active member of ESF. By the time of the study, he had enrolled for a professional course to enhance his promotion chances at work.

Munya's story clearly demonstrated his resilience and the strategies he used to overcome his challenges. Others had similar stories. From Munya's vignette – and the experiences of Munya, Hadeel, and others – it was clear that environmental factors, such as early treatment and a supportive family, had helped him remain resilient.

*Vulnerability*

Faced with numerous social challenges, most participants were vulnerable. Even those who were resilient had moments of vulnerability. Others had lost the confidence needed for job seeking and had given up looking for work. Yet others had psychological challenges. Mucha had become withdrawn in the workplace; Lameck had changed jobs; Rugare had worked harder; and Tindo, though she had worked hard, had stopped work, opting for self-employment, while Ashley and Tino kept on fighting.

Munya and Saru had become suicidal. Mucha recounted that, initially, he had become 'very stressed' following his retrenchment, He had gone 'into a huge depression' and had withdrawn from friends, who had disassociated from him, leading to his socially isolation. Some people had teased him, saying he was sick because his 'father had evil spirits or *chikwambo* [goblin]'. Mucha explained: 'I became a drunkard. I would go to the bar after school and get drunk. So that the community, when they say "things" [like I was possessed], I would not mind'. Saru, too, had contemplated suicide due to her social isolation: 'I had come to a situation where I even prayed behind my house that God should end my life'.

## Suggested strategies

Asked about effective strategies to deal with their employment challenges, participants mentioned epilepsy education, government services, nongovernment services, and individual management each of which is discussed in turn.

*Epilepsy education*

When asked about effective strategies to overcome misunderstanding and fear of epilepsy in their families, schools, workplaces, colleges and other institutions. Munya suggested epilepsy education for attitude change:

> It is the psychology of the people that should be changed. I had seizures and because of technical coincidences, I was convinced it was supernatural – I was bewitched. So, to me, that's our biggest challenge … People are scared because *they do not know. Lack of knowledge*. It's like a gun: you are afraid if you have never touched it. But you can make it safe. The one who understand it, there is no fear. It's all psychological (emphasis added).

By technical coincidences, Munya meant that, at times, cultural explanations were confirmed when things happened as predicted, even though this was mere coincidence. For example, when the explanation for Munya's seizures was that some of his relatives were jealous, as they did not want him to finish his university studies. These relatives were accused of having bewitched him. To Munya, this explanation fed on prevailing circumstances because people lacked proper knowledge about epilepsy.

Lack of knowledge about epilepsy led to unsupportive social reactions. Rufu felt that his family had not fully accepted and supported him. Thus, he saw the need for epilepsy education to start with parents:

> at times parents do not understand your condition. If they don't, who else will do? If parents accept you, it becomes easy to accept the condition ... So, I think parents should be educated too.

Masiziba believed education was needed to help people overcome their fear of epilepsy: 'They must not run away when seeing someone "fitting"; they should help the person or notify the

family about the situation'. Tonde and Thandiwe said the same educational strategies used to overcome the struggle to deal with the medical and social burden of HIV and AIDS could be used to deal with epilepsy. Tonde said 'First, the people we stay with must accept us as people just like people with AIDS have now been accepted. Even at work, they should accept'. Thandiwe believed that 'people should accept the condition. I think even HIV patients are worse than epilepsy. With epilepsy, you can still be very productive'. Tonde and Thandiwe suggested epilepsy awareness in schools, in teachers' training colleges, and in the community in order to create an epilepsy-friendly educational environment so people with epilepsy could acquire a tertiary education. Masiziba Munya, Lameck, and Edson agreed. More awareness was needed, along with better work policies and placements. Masiziba said employees 'should treat them the same as other employees and not to look at them as outcasts thinking that by associating with them they may end up also getting epilepsy'. Munya said, if employers were to take people with epilepsy for work placements, people with epilepsy would improve their work skills, while workplaces would improve their understanding of epilepsy and people with the condition. Referring to employers and managers, Lameck said:

> They need to have full knowledge about epilepsy. Employing someone with epilepsy is not something you can regret. People should do away with old tradition or myths that says epilepsy is transmitted. It's actually the opposite. They only need to know how to attend to an employee during a seizure ... I think maybe what they could do is to first avoid denial.

## *Government services*

Participants suggested strategies for the government, such as a quota system and informal sector support, to ensure access to training in epilepsy friendly colleges, where lecturers and trainers were educated about epilepsy. They suggested the government should be dealing with

corruption, allocating meagre public resources more efficiently, and focusing on meeting the needs of its citizens, rather than focusing on programs that are politically expedient. Farai said the government 'should accept people with epilepsy and understand their conditions … [and] help them find a suitable place to work'. Kocho, too, believed it was the government's responsibility to 'find a place where people like myself could work from'. Similarly, Nyari said:

> Government should introduce a quota system. At times when the current quarter system is used, companies do not consider epilepsy as a disability. Entrepreneurship must also be promoted so that people have a source of income. This will help because people with epilepsy will be financially independent.

Grace suggested that, if people with epilepsy failed to acquire formal tertiary education, they should get informal work-related learning to give them skills for both formal and informal jobs. Lameck said the government should assist with employing people with epilepsy in the public service, initiating self-help projects for them, embark on epilepsy awareness campaigns, and train people with epilepsy at its nursing and rehabilitation colleges to improve their employability. Mberi, Edson, and Tonde expressed similar views. Tonde added that government must engage employers and train them in 'how to do first aid and basic help in the event of epilepsy'. Grace, Simbi, and Nyari supported the view that government must engage in self-help projects with the support of nongovernment organisations. Nyari said the government must 'find for us people with epilepsy a place to trade from. A designated place for the disabled'. Others agreed, adding that the problems they faced in running small businesses required a more focused government approach. Tonde thought training in self-help projects was needed, observing that 'projects bringing people with epilepsy together are better because at workplaces they do not accept us'. Thandiwe, too, noted 'others are not getting jobs because of epilepsy. I think they should be helped get jobs. Perhaps provide work for them

where they work together as groups'. They would benefit from job placement, training, and other job-readiness programs. Grace said:

> The Disability Board must help us get courses in life. Being epileptic does not mean you can't do most jobs. You should do the job that you like. But only driving that people with epilepsy should not do.

Besides support with grants and projects, Sanga went so far as to say representation was needed for people with epilepsy in parliament under the banner of disability:

> I think they should have a representative of people with disabilities. They need to be understood. There is need for someone who knows what it takes to be with a disability. This representation is needed in parliament.

Saru added that parents and caregivers of people with epilepsy must be involved in advocacy, and must fight for the rights of people with epilepsy.

## *Nongovernment services*

Asked what more nongovernment organisations could do, Gab thought epilepsy awareness was especially needed in rural areas, while Lameck went further to say:

> I think their roles, their role, first, should carry out awareness campaigns. And, also, seek funding on behalf of people with epilepsy so that people can fund certain projects. The ESF may also give information to the general public … I was saying also for ESF; I think those organisations do not necessarily ask for donations. You know instead of giving a fish to a person, you need to teach them how to fish. They do not need to keep giving us donations. They should give us projects. If the ESF gives us projects, they improve our lives. But how do they do this? They start projects, so that people better their lives and the economy is improved. If they can get scholarships and other

educational facilities that will be good. People need to do projects on their own rather than depend on donors

Edson added that caregivers must be supported to provide the care and support required by people with epilepsy.  The nature of the support was not explained.

Asked how NGOs could improve their epilepsy services, Munya, Rune, Saru, and Edson said professionals, such as social workers, doctors, nurses, rehabilitation workers, and advocates could provide counselling, treatment, guidance, and mentorship. Munya called for better communication and dialogue and training for service providers in areas specific to epilepsy. Edson saw a need for more advocacy and epilepsy education (by professionals). Mberi recommended that NGOs should provide letters of support for people with epilepsy confirming their ability to work.

## *Individual factors*

Though the research focused primarily on structural issues, also important were individual factors, such as disclosure and adhering to treatment. Lameck said:

> Tell all the people [that you have epilepsy], at home, neighbours and even at work. Disclose to them. So that when anything happens, they know what to do … To improve employment, we have to be honest. Tell the truth once you find employment. Tell them … 'I have epilepsy'. That earns you trust from your employer so that even if you have a seizure, they will not say go out of my building. If you have trust, you will not have problems in future. Even if a relative phones your workplace when you are unable to go to work, the employer will understand. Avoid excuses to be fired. So, if from the word go people know that you have epilepsy, you will be okay.

Edson encouraged disclosure, as did Farai, though only once one gets work: 'They should disclose their condition and tell people to help them if first aid when they have seizures. In most cases people with epilepsy are shy to disclose yet they need help'.

Rune suggested treatment compliance: 'I try to follow up what the staff at the clinic tell me. Right now, I do not have seizures. I listen to their advice. They ask me to take medicines on time. I follow that'. He insisted that people with epilepsy 'must go to clinic, see prophets, to *n'angas* etc so that they get better'. Zoey, Tonde, Rufu, and Rugare also encouraged people with epilepsy to take their medicines. Rufu went further to suggest reducing triggers like alcohol. Munya and Lameck encouraged people with epilepsy to be role models, in addition to dealing with triggers and side effects. Munya said role models did not give up easily; they pursued treatment; they disclosed their condition, and encouraged others to do the same. Lameck said society lacked people with epilepsy who were willing to stand out and speak about their situation. Lameck suggested role models could appear on television and radio programs to reach out to society with correct information.

## Conclusion

This chapter presented the findings from the in-depth interviews with people living with epilepsy, outlining their varied experiences that shaped their employment opportunities. Such experiences related to beliefs, reactions, and practices; gaining work skills; job seeking; workplace attitudes and practices; support services, and self-management. Participants made suggestions to improve their situations and these related to epilepsy education, government and nongovernment services, and individual factors. As pointed out in Chapter 4, service providers were asked about their perspectives on these findings in a focus group discussion. Chapter 8 presents the findings from the focus group discussion.

# CHAPTER 8

# Findings: Service-provider perspectives

This chapter presents the findings from the focus group discussion with service providers (n=7). As outlined in Chapter 6, the aim of including service providers were twofold: (i) to expose them to employment experiences of people with epilepsy with a view of scaling up the employment services they were providing; and (ii) to get their perspectives on findings from interviews view to deepen understanding. The researcher provided the service providers with a preliminary report on the findings from the in-depth interviews with people with epilepsy (included in Appendix 1). The chapter begins with a profile of service providers shown in Table 8.1, and of the preliminary report presented to service providers, as shown in Table 8.2, followed by themes emanating from the focus group discussion. It then compares views of service providers and people with epilepsy, and ends with a discussion of possible lessons for service providers.

## Profile of service providers

The service providers who participated in this research:

- Comprised four females and three males.

- Had been in service for a combined 43 years, mean of six years.

- Comprised two health workers, three social service workers and two advocacy workers.

- Comprised three with university degrees, two with diplomas, one with a certificate, and one had received on-the-job training.

Further information about the service providers is summarised in Table 8.1.

**Table 8.1: Profile of service providers**

| Service provider | Gender | Position | Role |
|---|---|---|---|
| 1 | Female | Social service employee for three years | Assessment, counselling, outreach, and supervision of support groups |
| 2 | Female | Nurse for one year | Diagnosis, consultation, and dispensing medication |
| 3 | Female | Assistant nurse and information officer for five years. | Initial assessment and referral and information provision |
| 4 | Female | Counsellor for 12 years | Counselling and support |
| 5 | Male | Advocacy employee for 14 years | Advocate for the rights of people with epilepsy |
| 6 | Male | Peer supporter for five years | Peer support, referral, and information provision |
| 7 | Male | Advocacy employee for eight years | Counselling, information provision, referral, and training |

## Summary of preliminary report presented to service providers

As mentioned earlier, service providers, who participated in the focus group discussion, were first provided with a preliminary report of the findings from the in-depth interviews with people with epilepsy. Table 8.2 presents a summarised version of the report. It shows the experiences, factors (facilitators and barriers), and effective strategies suggested by people with epilepsy.

## Perspectives of service providers

The main themes arising from the focus group discussion related to experiences, factors, and effective strategies, as shown in Table 8.3. Themes emerging from the focus group discussion included job-seeking and workplace environment, policies and legal recourse, education and training, treatment of epilepsy, 'triple burden' of women with epilepsy, epilepsy as a 'neglected condition', ESF services, and self-management and family support.

**Table 8.2: Summary of preliminary report presented to service providers**

| Experiences | Factors acting as facilitators or barriers | Effective strategies |
|---|---|---|
| Participants were viewed as sick, mentally ill and less productive. | Epilepsy misconceptions and attitudes. | Stigma reduction through epilepsy awareness. |
| Most participants did not get the education and jobs they wanted. | Primary, secondary and tertiary education. | Employment services such as career guidance and training. |
| Participants lost jobs once it was known they had epilepsy. | Employment services. | An affirmative action policy to reserve and create specific jobs for persons with disabilities. |
| Some participants shared successful stories of getting education and attaining jobs. | Individual reaction to epilepsy. | People with epilepsy who succeeded should be role models. |
| Situation of participants improved after medical treatment. | Health services. | Medical treatment. |
| Participants said some families were supportive yet others were protective. | Family reaction. | Increase understanding of epilepsy and acceptance of people with epilepsy. |
| Participants said the job environment was difficult in both public and private workplaces. | Employer and co-worker attitudes. | Workplace education and adjustments. |

## *Job-seeking and workplace environment*

### *Difficulties in accessing employment*

A key theme emanating from the in-depth interviews was that securing and maintaining jobs was difficult once it was known that the jobseeker had epilepsy. Service provider 4 expounded on this, saying it was common for people with epilepsy to have negative job expectations because of the fear attached to their condition. Service provider 4 added that private sector jobs were more difficult to come by and keep, as compared to government jobs: 'Actually, our government is supporting people with epilepsy; it's not stigmatising or discriminating against

anyone with a condition of epilepsy' (Service provider 4). But Service provider 5 argued, saying the government favoured visually impaired people and it was difficult to collect statistics on the employment of people with epilepsy as many did not disclose their condition.

**Table 8.3: Themes from focus group data**

| Themes | Nodes and sub-themes |
|---|---|
| Job-seeking and workplace environment | Difficulties in accessing employment. Negativity and doubt. Affirmative action. Individual job-seeking skills. |
| Policies and legal recourse | 'Court battles not fought'. 'People with epilepsy must be their own advocates'. Human rights approach. |
| Education and training | Education and training. |
| Treatment of epilepsy | Medical treatment. Traditional treatments. |
| 'Triple burden' of women with epilepsy | 'Triple burden' of women with epilepsy. |
| Epilepsy as a 'neglected condition' | Epilepsy as a 'neglected condition'. |
| ESF services | ESF services. |
| Self-management and family support | Self-management and family support. |

Though the government employed people with disabilities, Service provider 5's experience was that people with epilepsy found it hard to access employment in the public sector, whether or not they disclosed their condition. The participants agreed that, outside the study sample, very few people with epilepsy were employed, even by government. They attributed the low employment rate to the lack of employment support services, especially in career guidance and training, which needed to start with children at primary school. Service provider 2 had encouraged the government to resume these programs because: 'It's important to provide guidelines on how children growing up can choose a profession'.

*Negativity and doubt*

Interview participants experienced negativity and doubt in the workplace once it was known they had epilepsy. Focus group participants agreed but debated the merits of disclosure. Service provider 4 outlined the dilemma:

> When seizures are controlled, a person can live a normal productive life, as earlier mentioned. Therefore, if someone is employed, he or she may choose not to tell the employer ... If you mention you have epilepsy you may lose the job. But if the seizures are controlled, you can choose not to tell your employer and you can lead a normal productive life.

Service provider 5 was equally ambivalent, saying that given the stigma of epilepsy as a disability and chronic medical condition, people should not be forced to disclose, adding we also have 'to protect my interests as a person with the condition'.

*Affirmative action*

Interviewees proposed affirmative action to reserve a jobs quota for people with epilepsy. Service provider 7 did not think this was a good idea but believed that affirmative action compounded the situation whereby certain types of positions would be labelled jobs for people with epilepsy. Nevertheless, he thought the government could reserve one in ten jobs for people with disability, including epilepsy. His thinking was that, if jobs were reserved for people with epilepsy only, instead of people with disability generally, people with epilepsy would be accused of 'making situation worse' (Service provider 7). Service provider 5 agreed, arguing for mainstreaming disability rather than epilepsy *per se*. It had worked for the gender movement and could work for disability, argued Service providers 5 and 6. Though Service provider 6 supported affirmative action, arguing that most people with epilepsy were not

considered disabled, most of the focus group participants advocated mainstreaming rather than affirmative action.

## *Individual job-seeking skills*

Service provider 1 believed that some members had given up looking for jobs, due to negative attitudes towards people with epilepsy and the possibility of losing their job following disclosure. Equipping people with epilepsy with job-seeking skills and educating employers were major priorities, said Service provider 1. Service provider 1 further argued that some people with epilepsy 'expect white collar jobs' rather than informal employment. Service provider 1 believed some families overprotected members with epilepsy and prevented them from seeking work because: 'Our society looks down at people with epilepsy', seeing them 'as sick'. She believed overprotection was wrong: 'There is need for empowerment even if they do not get work in an economy like this, where jobs are not there for those educated and those not'. Service provider 2 agreed, adding that over protection arose from a lack of awareness. While the ESF was conducting 'workshops for bankers and defense professionals trying to bring awareness', more work was needed in this area, argued Service provider 2.

## **Policies and legal recourse**

### *'Court battles not fought'*

The focus group participants wondered why concerned parties faced with discrimination at work did not go to court. Service provider 7, an advocacy officer, said:

> [I want to comment on] legal issues or legal battles concerning people who may have been dismissed from work. Those people after being dismissed from work are wondering about survival and they are wondering if they have enough money for legal teams. Can you use the little money to pay a lawyer and use the little money [for

survival]? It's not an easy battle. At times, it's done on medical grounds, after doctor's assessment who said you are not fit for work. The courts may say it's not urgent, it may drag for years. Paying fees without a means of survival it may take time, the lawyer has to be paid, and you need to feed your family. That's why these battles are not fought.

His view was that people with epilepsy would like to settle their disputes in court, but numerous obstacles stood in their way among them inadequate income, delays at court and unavailability of adequate health assessment.

## *'People with epilepsy must be their own advocates'*

Service provider 5 believed that people with epilepsy 'must be their own advocates'. However, once on treatment with seizures controlled, many did not want to stand out as role models and advocates. Thus they shy away from epilepsy activities in public. Service provider 1 explained:

They are not bold enough to come out in the open to let other people know how they overcame their challenges with epilepsy. There is a need for us to have ambassadors, people willing to go out there, to raise awareness, to share their stories with others. So, we still have a long way to empower people, to find people who can do that.

If forced into advocacy roles, many would stop using ESF's treatment services and seek private healthcare. Service provider 4 believed the starting point was acceptance and building self-esteem. Once this was achieved, people with epilepsy would become strong ambassadors for those with this condition.

## *Human rights approach*

Participants, being professionals, offered insights into disability models and their application to the epilepsy field. Reflecting on the researcher's stated objective of wanting to develop an

epilepsy-management model at the end of the study, Service provider 7 stated that the government must emphasise the human rights model:

> I was thinking about this vicious cycle you [researcher] were talking of … I think … government … is mixing the charity and medical model with no focus on [the] human rights model. If government emphasises the human rights model, I think things will be okay, e.g., in this vicious cycle, there is no education [but] joblessness, so if a human rights approach is used, it's the rights of anyone to have education, whether with epilepsy or not.

Service provider 7 expressed concerns about the lack of rights to education, health, and housing and believed a human rights approach would lessen the burden of epilepsy. Service provider 7 was optimistic that the researcher would find an appropriate model to advance recognition of the rights of people with epilepsy in Zimbabwe.

## *Education and training*

Interview participants pointed to the many challenges affecting their education at all levels. Service providers agreed saying that education enhanced employment opportunities. Service provider 5 blamed the education system for the situation of people with epilepsy, saying society labelled them as incapable, limiting their educational opportunities:

> Those [people with epilepsy] who excel through it's either by force or by God's grace. If you look at the environment at schools, it's not conducive for a person with epilepsy. One, teachers are not equipped to handle children with epilepsy. As an example, at one school the headmaster told the parents 'take away your child; bring child when better'. What does that mean? Where will she take that child? You see, hence, it's just a way in which the system is discriminating against the person with epilepsy. That's why it is

important to have anti-discriminatory laws to protect and prevent such acts by …

headmasters … they think that sending the child back home and taking that initiative to

help the child is a waste of time.

He said it was always important to have school teachers and headmasters who knew how to

deal with children with epilepsy. He recommended improving teacher training. However,

Service provider 3 thought the parents were to blame for their children's poor education:

Our members [people with epilepsy], some of them just did grade seven because those

who take medication at times they lose memory. They fail grade seven and if this

happens the parents will say you are wasting our time you can't proceed with school.

They are asked to sit at home doing nothing. But they forget the person is taking

medication, and is able to proceed with school. But they blame the person saying you

are failing school, yet it's because of seizures.

By year seven, Service provider meant year that is the final year of primary education in

Zimbabwe. Service providers 3, 4, and 5 agreed. Service provider 4 said, at times, it was not

about a child not doing so well at school, but rather concerned the parents' fear of sending their

child lest they have seizures. Service provider 4 said parents were afraid their children would

not receive the help they provided at home and suggested that teachers should be taught

epilepsy management to increase the parents' confidence. Despite these challenges, the focus

group participants stressed the importance of having the necessary qualifications if people with

epilepsy were to do well in employment. Service provider 1 thought that ESF should encourage

the younger generation to seek services to ensure that they went to school and nurtured their

talents. Service provider 5 talked about ensuring that people with epilepsy 'thrived in the

environment as opposed to the current situation' focused on theoretical knowledge rather than

practical employment skills.

### *Treatment of epilepsy*

### *Medical treatment*

Focus group participants agreed that the interview participants had all received medical treatment services, since they were all members of the ESF. They said people in the urban areas had greater access to treatment but the rural treatment gap remained high. However, they bemoaned the delays in receiving medical treatment and the lack of effective medical treatment services the interview participants had experienced. Service provider 5 said many people with epilepsy delayed medical treatment as they did not know that epilepsy was a treatable condition: 'There is lack of knowledge within communities', while, for those participants who had a rural background, 'there are no clinics in those areas they have to travel [on foot] for more than 40 kilometres or board a bus [adding to their expenses]' (Service provider 5). Others agreed, adding that health centres did not usually have an adequate supply of anti-epilepsy medicines and most lacked nurses trained to manage epilepsy, the unavailability of doctors notwithstanding. Although services were much better in urban areas, they were still basic and unaffordable for many, hence the attraction of the ESF. In summing up the discussion, Service provider 2 stressed the need for medical treatment as this could result in a reduction of stigma and discrimination and increased opportunities because 'you will not be confined', you will be able to 'go out and work be it formal or self-employment'. Service provider 2 stressed the need to reduce fear, and negative beliefs and practices through awareness at home, in the community, and in the workplace.

### *Traditional treatments*

Interview participants shared experiences of traditional treatment and beliefs about epilepsy in their communities. Focus group participants were familiar with their experiences. Service provider 2 blamed traditional beliefs for delayed medical treatment, stigma, and fear:

181

Most of them [interview participants] had in their life probably … tried alternative spiritual or traditional treatment and the last option was going to hospital or to ESF. Considering if they had sought treatment earlier, they probably would have been controlled and, who knows, he or she would have gotten a job earlier. To come to where they did not expect to get a job is due to the delayed treatment they had. So, I think delayed treatment played a part.

Service provider 1 agreed, saying once people with epilepsy were successfully treated, they could lead a normal and productive life and nothing could hinder them from taking work. But, in most cases, they delayed treatment. Service provider 2 added that '…coming to ESF or coming to a medical centre will be last resort, or last plan, it will be last measure in most cases', while Service provider 4 elaborated on why people sought traditional treatment first:

If someone is asked to take medication for the rest of their life, they do not want it. At the end of the day, they do anything within their means to make sure that the seizures have stopped and traditionally it is assumed that if you are treated by a traditional healer the seizures will stop, so people will make sure they do anything else to ensure that their seizures are stopped and to ensure that there is no medication that is taken because people are terrified of taking medication for the rest of their life which is why maybe the hospital is the last port of call for [our] members.

Service provider 1 concurred that the misconceptions surrounding epilepsy resulted in people going to traditional and faith healers and that, in most cases, people with epilepsy started with traditional treatment, which did not heal them, despite their use of resources and time. An example was given of a family that smeared chicken manure on a child with epilepsy for a prolonged period to no avail until they heard about the services at the ESF. The focus group participants agreed that people consulted witch doctors, prophets, and other faith healers due

to the ongoing belief that epilepsy was associated with evil spirits and witchcraft. They explained that a diagnosis of epilepsy, when made by traditional healers, was often stressful for the family, as it amounted to an accusation of spirit (evil goblins) possession, wickedness, and sin. These pervasive erroneous beliefs increased stigma for individuals and their families, argued Service provider 3. However, it was not clear whether the stigma reduced once people were traditionally treated or not.

Service providers agreed on the need for research into herbal medicines because some of their clients claimed to have been healed temporarily following herbal treatment. Service provider 5 said the Ministry of Health should support research into traditional medicines and provide strict monitoring of practitioners of traditional medicines. Service provider 4 was especially worried about prophets who provided Christian treatments, while discouraging people with epilepsy from taking medication. Service provider 7 was concerned about *tsikamutanda,* traditional healers engaged in witch-hunting, who exorcised 'evil spirits', because they too discouraged medical treatment.

### *'Triple burden' for women with epilepsy*

As well as living with a stigmatised condition, focus group participants agreed that working women with epilepsy experienced additional challenges related to their family roles. As Service provider 1 explained:

> Maybe it's issues like, at work you are being discriminated. As a mother, maybe, in the family they look down upon you and then in the community people look down upon you [as well]. Women with epilepsy face [several] challenges. We can give examples on contraceptives, there is an issue of drug interaction so you find that the challenges are many for an individual, that is why it's a triple burden.

Service provider 5 added that women in Zimbabwean society were subservient to men, and having epilepsy worsened their position. Work added to these challenges: 'It's a triple burden. Already women have been marginalised over the years and now because a child has a disability, we have certain myths and misconceptions regarding females with disabilities' (Service provider 5). Asked to explain further, Service provider 5 said there is a misconception that if a sick male has sex with a disabled female, especially a child, the male person will be healed. Expanding the debate on the 'triple burden', Service provider 6 enlarged thus:

> In relation to triple burden, as workers they should provide for their families under conditions that can trigger seizures. The environment may not be conducive. As mothers, they are married, they are wives. The family has a lot of expectations like cooking on a fire with flames yet flames trigger seizures. They should fetch water from dam or well but this can trigger seizures. If this happens, family will say she is lazy. The seizure is used as a tool to blame her yet there are things happening. Then as a wife or as a mother, the husband may raise issues to do with infidelity, e.g., why are you doing this, you are cheating on me. Some husbands can blame you for different things. They blame you for infidelity. A triple burden they are faced with.

Asked to explain on fidelity, Service provider 6 said at times epilepsy medicines lower sex drive but partners might not understand this effect. Service provider 3 suggested that, to deal with this triple burden, women should have support groups to encourage one another so they could deal with stigmatisation. Thus, the importance of psychosocial support for women with epilepsy to help them accept and manage their condition.

### Epilepsy as a neglected condition

Service provider 5 believed the government was biased towards employing people with physical disabilities rather than those with neurological conditions. This extended to other

institutions of education. Service provider 5 provided two examples. In Vignette 8.1, an ESF member, who had been given a scholarship to study at the University of Zimbabwe, had the offer withdrawn once his epilepsy was discovered.

**Vignette 8.1: Is epilepsy a disability?**

The University has a scholarship for people with disabilities. Under this program, as long as you have a disability, everything is covered, fees and accommodation. But we have clients that have been chased away. One [of our clients], the first semester, he learned under the scholarship but in the second semester, when they realised that his disability was epilepsy, he was asked to pay. We now ask why there is segregation of these disabilities when you are accepting some and rejecting others. Zimbabwe is a signatory to the CRPD, but discrimination happens an institution with a disability resource centre, I think issues of antidiscrimination laws are required.

The second example, Vignette 8.2, was from Service provider 5's experience, since he was living with epilepsy.

**Vignette 8.2: 'I want to see how a person [with epilepsy] is disabled'**

I was in a disability workshop that was being chaired by a Chief Executive Officer (CEO) of a government institution. As a participant, I stood to ask a question but the CEO kept saying 'I want to see the person standing up and I want to see how this person is disabled'. He said '…how come you are not disabled?' I told him when I introduced myself I said my disability, which is epilepsy. I explained that in terms of the government of Zimbabwe, epilepsy is a disability.

Service provider 7 explained that the Zimbabwe constitution and the Disabled Persons Act did not adequately consider all forms of disability and this loophole was used by

institutions to deny services to people with epilepsy. Service provider 5 advocated a barrier-free, anti-discriminatory law that would foster equal opportunities regardless of the type of disability. Service provider 7 believed the government's failure to define disability clearly was a major problem:

> I think … we have an institutional problem. For example, straight from the government, we do not have a clear definition of disability. Therefore, a department at the University of Zimbabwe may even choose to say this is disability and this is not disability. So, I think we should have it from the constitution then a policy so that people can be held accountable. If it was clearly stated in our constitution, there is no way DRC [Disability Resource Centre] could have said those with epilepsy are not disabled. I think we have a problem with the government and the institutions (Service provider 7).

Focus group participants seemed to agree that epilepsy was neglected both as a disability and a chronic health condition. In addition to the examples given in Vignettes 7.1 and 7.2, they said health services were poor, with an under supply of medicines and inadequate personnel. Service provider 5 wondered why epilepsy was managed under psychiatric condition by the Ministry of Health and why the country had no neurologists, a situation that resulted in psychiatrists managing most epilepsy patients who required specialist services. Service provider 2 added that even under the circumstances, there was no specific program or budget for epilepsy within the Mental Health Unit that was mandated with leading the Ministry of Health in epilepsy management.

### ESF services

Interview participants had resorted to NGO services once they failed to secure adequate government support. The focus group participants enlarged on the importance of NGO

services. Service provider 2 said that, ultimately, people would try free or subsidised treatment, such as that provided by the ESF. Service provider 2 gave an example of a service user who had come to the ESF from rural Mudzi after hearing an epilepsy awareness program on the radio. He had 'had enough of traditional healers'. Following consultation with the doctor at ESF over several months, the Mudzi service user had returned to express his appreciation: 'Thank you so much. My daughter used to have several seizures a week now she is having about four months [between seizures]. We are happy. If we come again, then she will be fully controlled'. Service provider 2 also talked about soft skills, like self-esteem, that they had provided to members over the years saying these skills included building self-motivation, self-reliance, and acceptance. Service provider 5 believed the ESF's advocacy and awareness programs had helped people with epilepsy build acceptance in the absence of a strong policy framework to support its work:

> From an advocacy perspective, we now look at issues of policies and legislation. The current legislation, for example, the Mental Health Act, does not include anything about epilepsy ... You go to the Education Act, yes it talks of inclusivity but when you go to the definitions, it's not very clear … In terms of job opportunities, these can only be created if a person does not disclose … once you state that you have epilepsy, ahhh, kiss your job goodbye … And personally, I would want the social model to take a lead in the sense that it looks at the rights of an individual, for example, what are your aspirations, what is it that you want to do or achieve, yes you can treat me and then, what? If you look at the majority of our clients, some of their seizures have been controlled and then, what next? They continue to ask, is there anything happening. You know, there is nothing more we can offer besides medical treatment that we provide.

Service provider 5 was critical of the limitations imposed on the work of the ESF by a lack of government support saying that the organisation provided social support but this was not

enough. Service provider 5 said the services were 'not comprehensive' enough and advocated use of the social model to give clients the opportunity to decide for themselves, instead of having 'an institution or another officer or person deciding for you'.

## *Self-management and family support*

A recurring theme for interview participants was the need for self-management and family support. Focus group participants agreed this was important for improving employment opportunities. Service provider 3 emphasised that people with epilepsy needed the skills to manage their treatment, epilepsy triggers, and the side effects of medication or this would impact on their ability to work. Service provider 3 said issues encountered included work events or stresses that triggered seizures, such as the over use of computers or loud noises, the side effects of medication that made them dizzy, and ineffective treatments. Others agreed. Service provider 1 said the side effects of medication were due to a lack of proper epilepsy management because some medicines were inferior and less effective. Service provider 2 said family support was needed to help the person with epilepsy manage their condition and employment, however, often the family lacked understanding of the condition. Hence, awareness-raising should play a bigger part, beginning with the family, suggested Service provider 2.

## Comparison of perspectives of service providers and people with epilepsy

### *Perspectives on epilepsy*

Both interview and focus group participants agreed that epilepsy was disabling because it was a much-neglected chronic health condition but service providers provided vignettes showing existing gaps in legislation and specific examples of discrimination based on epilepsy. Focus group participants said there was minimal government support for the treatment of epilepsy as

it was seen as a disability rather than a treatable condition. Interview participants had pointed out that employers did not see a need to make changes to accommodate their special circumstances or to educate co-workers. Interview participants viewed epilepsy from a biomedical and disability perspective, while some saw it as a supernatural condition. Interview and focus group participants had consensus on these issues:

1. Stigma, negative beliefs and misunderstanding were rampant hence the need for awareness. This resulted in limited opportunities in education, training and work.

2. Seizure control improved opportunities in education, work and social life like marriage.

3. Epilepsy was not fully recognised as a disability hence the need for human rights approach.

4. People with epilepsy had no access to public employment services and employment services of NGO were weak.

5. Women with epilepsy faced extra challenges.

6. Courts were not accessible because of cost, and fear of not succeeding.

7. ESF played a crucial medical and social role but not economic.

But there was no consensus on:

1. Traditional treatments.

2. Disclosure at workplace.

3. Affirmative action.

4. Which of public or private sector employers were better.

A new idea, not found in the literature and not mentioned by people with epilepsy but mentioned in the focus group discussion was that some people with epilepsy delayed medical treatment because they did not want to take medicines or to take them for prolonged periods of

time. Though the experiences of people with epilepsy showed individual resilience, and they described it using different words like fighting spirit, more emphasis was placed on individual resilience by service providers.

The argument that people with epilepsy were afraid to take medication for the rest of their lives was a new idea that Service provider 4 brought into the discussion. This idea had not been mentioned by people with epilepsy. This was considered one reason why people have medical treatment as a last resort while focusing on traditional treatment. This could indicate the labelling attached to taking medicines in Zimbabwean society or the competition between traditional and medical treatment. While some interview participants supported and embraced traditional treatments, focus group participants were adamant about the proven effectiveness of medical treatment and doubted the efficacy of traditional measures.

## *Perspectives on effective strategies*

While interview participants supported jobs reservation for people with epilepsy, focus group participants expressed ambivalence about this. They tended to support the mainstreaming of employment services, such as career guidance and skills training, rather than affirmative action. Both groups agreed, however, that effective medical treatment was crucial for employment.

Most interview participants proposed individually focused strategies that were welfaristic in nature, while focus group participants suggested structural strategies of state provision. Neither group had embraced a developmental approach to addressing employment challenges. Welfare perspectives predominated though focus group participants expressed a strong need for a social model and human rights approach although their suggested approaches did not strongly support a focus on employment. Neither group provided strategies for long-term planned interventions to deal with employment issues. Interview participants were not clear on what the government could do and tended to focus on what NGOs could do.

## Possible lessons for service providers

The focus group discussion sought to provide service providers the opportunity to hear service-user views on employment. One important lesson flowing from this was the importance of focusing on employment issues. To a lesser extent, lessons includedt need to focus on structural barriers and need to address policy gaps. The focus group participants involved in healthcare at the ESF indicated their detachment from employment issues but the focus group discussion encouraged them to see treatment as part of an integrated service that included employment, education, and legal support to achieve a good quality of life for people with epilepsy. The focus group discussion encouraged participants to reflect on this shortcoming. Focus group participants indicated that they had not taken employment issues seriously, as they believed opportunities for getting jobs was limited for people with epilepsy because of their condition and because the economy had not enough jobs for everyone. Following the focus group discussion, they shared a sense that employment issues had a major impact on the health, social, and psychological status of their clients. Despite a poor economy and epilepsy, it was still possible for their clients to have better employment outcomes than they experienced.

Following the focus group discussion, service providers were faced with the realisation that the problems experienced in finding and maintaining employment were greater than individuals. The problems emanated from lack of policies and resources, and also lack of recognition of epilepsy as both a health and disabling condition. These barriers made it difficult for individuals with epilepsy to break employment barriers standing on their way.

After the focus group discussion, it is hoped, service providers realized the real policy gaps that exist and stand as barriers to the work they did. The first gap pertains to the position of epilepsy as a disability yet it was not fully considered as such. People with physical disability were seen as more disabled in Zimbabwe. The second and last gap pertained lack of policy

framework that supports epilepsy management in the country. The existing policy favored psychiatric treatment. These two gaps could be used to enhance advocacy.

## Conclusion

This chapter presented findings from the focus group discussion with seven service providers at the ESF. There was agreement on barriers people with epilepsy faced in employment. Service provider's perspective was that the barriers included lack of epilepsy knowledge in the family and society, and limited access to education, training, welfare, health and legal services. There was agreement on the extra burden women with epilepsy faced. Though there were some areas of variance between the views of interview and focus group participants (such as on disclosure and individual factors), all agreed that people with epilepsy needed to work an extra mile to achieve better employment outcomes in context of less than ideal government support services. One lesson service providers could have gained from their involvement in the research was that problems experienced in finding and maintaining employment were more structural yet the services they provided were more individualistic. The final chapter discusses the findings reported in Chapters 7 and 8, the study's conclusions, implications, and suggestions for future research.

# CHAPTER 9

# Discussion, conclusions, and implications

This chapter discusses the findings presented in Chapters 7 and 8 along with the main conclusions of the study. The discussion is organised into five main sections, as shown in Table 9.1. They are: (i) negative impact of beliefs about epilepsy; (ii) ongoing gaps in public services; (iii) challenging job-seeking and workplace environment; (iv) self-management and individual factors; and (v) effective strategies. Attention then turns to the study's implications for social policy, epilepsy work in Africa, and social work. The chapter ends with suggestions for further research.

### Table 9.1: Main findings of the study

| Findings | Details |
|---|---|
| Negative impact of beliefs about epilepsy | Persistent misunderstanding and ignorance of epilepsy led to social exclusion. |
| | Persistent trust in ineffective traditional treatments – led to delayed seizure control. |
| Ongoing gaps in public services | Lack of educational and vocational support services. |
| | Lack of public social welfare and public disability services. |
| | Medical health services were expensive and difficult to access. |
| | Reliance on nongovernment support services. |
| Challenging job-seeking and workplace environment | Job-seeking challenges. |
| | Persistent barriers in the workplace. |
| | Gender issues in the workplace. |
| | Absence of employment services. |
| | Lack of recourse to justice in the workplace. |
| Self-management and individual factors | Self-management, resilience and vulnerability. |
| | Individual factors. |
| Effective strategies | Epilepsy education. |
| | Government services. |
| | Nongovernment services. |

## Discussion

### *Negative impact of beliefs about epilepsy*

### *Persistent misunderstanding and ignorance of epilepsy led to stigma*

Misunderstanding, ignorance, and inaccurate cultural and religious beliefs persisted that epilepsy was caused by, and manifested, an evil or avenging supernatural spirit. People with epilepsy, seen as mediums of evil spirits were, therefore, feared. These inaccurate beliefs had detrimental effects and contributed to a devaluing of people with epilepsy in the family, community, school, and workplace.

Family members, friends, neighbours, teachers, health workers, employers, co-workers, and the general community harboured negative views of epilepsy. Hence, epileptic seizures became a mark of undesirability in society, resulting in social stigma, as described in the seminal work of Goffman (1963). Stigma of people with epilepsy gave them an unhelpful identity as people without social and economic value thereby misrecognising their needs, an indication of cultural injustice (Fraser, 2005; Honneth, 1997; Kilinc & Campbell, 2009; Obeid, 2008).

In Zimbabwe, stigma was institutionalised in Christian churches and indigenous cultures. It served no other purpose than being a conduit of social exclusion. People with epilepsy and service providers who participated in the study agreed that a sequence of barriers culminated in poor employment outcomes for people with epilepsy. At the base of this sequence lay cultural and religious beliefs that sustained ineffective traditional treatment practices for epilepsy. These beliefs fostered negative social attitudes that resulted in fear, stigma, and exclusion, leading to delayed medical treatment, and compromised education and vocational training – key factors for positive employment outcomes. This was compounded by poor public services. Hence, the chances of attaining or maintaining employment were reduced.

The study confirmed prior findings on the role of negative social attitudes in reducing the quality of life of people with epilepsy in Zimbabwe (Madzokere, 1997; Mielke et al., 1997; Mugumbate & Mushonga, 2013; Saburi et al., 2006), in other African countries (Birbeck, 2000; Duggan, 2013; Halima et al., 2017; Hounsossou et al., 2015; Keikelame & Swartz, 2015; Mushi et al. 2011; Nuhu et al., 2010; Watts, 1989, 1992) and worldwide (Baskind & Birbeck, 2005a; Bishop, 2002; de Boer, 2010; Elger & Schmidt, 2008; Kilinc & Campbell, 2009; Meinardi et al., 2001; WHO, 2015). In Senegal, Halima et al. (2017) found that employed people with epilepsy were feared and looked down upon and this impacted on finding work and job promotion. Findings related to these were found in Benin, where Hounsossou et al. (2015) reported that epilepsy was considered contagious, which reduced willingness to employ people with epilepsy. In Malaysia, Wo et al. (2016) found that stigma lowered employment. In this study, negative social attitudes were found to act as barriers to socialisation, treatment, education, training, and employment opportunities for people with epilepsy. For most, persistent ignorance about epilepsy had led to stigmatisation and isolation and ongoing fears, not only in the workplace, but also in school. Headmasters, teachers, and fellow pupils feared people with epilepsy, which led to their social exclusion. Bishop (2002) reported similar findings found in Senegal and Malaysia. In Zimbabwe, as in all these countries, persistent misunderstanding of epilepsy was a major barrier to employment.

Service providers were all too aware of these barriers to social inclusion for people with epilepsy, highlighting ILO (2015)'s view that community-based, nongovernment services, such as those provided by ESF, were extremely important for people with epilepsy. ESF played an important role in educating people with epilepsy and their families, giving them access to treatment and support. Awareness enhanced understanding of epilepsy as a medical condition and increased treatment uptake and control of seizures to counter the social exclusion and isolation of people with epilepsy. However, many people in Zimbabwe harboured negative

social attitudes bolstered by unscientific and superstitious religious and cultural beliefs. It was, therefore, unsurprising that people continued to fear epilepsy and its consequences. These beliefs formed the basis for cultural and religious interventions, resulting in the seemingly endless competition between traditional and medical treatment.

*Persistent trust in ineffective traditional treatments led to delayed seizure control*

Traditional treatment, which included cultural and religious interventions, was the first port of call in line with local beliefs. This confirms previous findings in Zimbabwe (Adamolekun, Mielke, & Ball, 1999; Mutanana & Mutara, 2015). This situation was not peculiar to Zimbabwe, but existed in African countries like Nigeria, Uganda, Tanzania, Zambia and Malawi (Birbeck, 2000; Duggan, 2013; Mushi et al 2011; Nuhu et al., 2010; Watts, 1989, 1992). ILO (2015, 2017) argued that negative attitudes towards people with disability result in poor employment outcomes. There were several reasons for this trend in this study. First, the reliance on cultural remedies and religious solutions was as much a factor of some erroneous beliefs as of their ready availability within the community, as well as the tremendous power enjoyed by traditional healers in Zimbabwe. Second, cultural and religious healing was a well-embedded social institution and an industry that generated livelihoods for its practitioners − prophets, church owners, traditional healers, and herbalists, who were legitimate authorities (Chitando et al., 2013; Watts, 1989). Third, for people with epilepsy and their families, these cultural and religious healing practices offered an accessible, affordable solution, made more attractive by the lack of affordable medical treatment (Biskand & Birbeck, 2005, 2005a; Magazi, 2017). Ready access to traditional treatment led to delayed medical treatment, which, in turn, led not only to social problems relating to education, training, and employment, but also to psychological and mental health issues and social isolation (de Boer, 2010; Elger &

Schmidt, 2008; ILAE, WHO, & IBE, 2000; Meinardi et al., 2001). Fourth, through attending traditional ceremonies and events such as church gatherings, psychosocial support was provided to people with epilepsy, and this was important given the lack of psychosocial support initiatives such as counselling. This explanation would fit participants prior to visiting the ESF. Fifth, but not least, traditional healers offered hope and usually promised quick healing, including apportioning blame to witches (Chitando et al., 2013; Jackson & Mupedziswa, 1988).

The focus group discussion provided new insights into why people with epilepsy delayed medical treatment in favour of traditional treatments: taking medicines especially for prolonged periods was not favourable, and was often discouraged in Zimbabwean society. Because of this, medical treatment was taken at the last resort. And even so, medical treatment was often stopped. This sounds a plausible explanation into delays in getting medical treatment and reasons for defaulting medical treatment. However, there could still be other reasons making this possible. These include poor public services. In the eyes of Fraser (2008, 2011), the lack of public services represented economic injustice, especially so considering that HIV and AIDS programs and other politically expedient programs were being adequately funded by the government.

There was competition between traditional and medical treatments in Zimbabwe, as in Africa generally (Dekker, 2002; Magazi, 2017; WHO, 2016; Winkler et al. 2009). This competition rested on several factors. First, people with epilepsy continued to use traditional treatments, which service providers did not promote and health workers did not overtly though might clandestinely support due to their cultural embeddedness. Secondly, Zimbabwe's laws and institutions promoted the use of traditional and medical treatments. People with epilepsy, and Zimbabweans in general, were caught between two worlds, the scientific, where medical treatment has proven effectiveness in controlling epilepsy and sociocultural, where traditional and religious practices encourage ineffective treatments undergirded by strongly held beliefs

in the supernatural. Thirdly, traditional treatment practice has proved remarkably resilient in the face of strong competition for market share from medical practice and pharmacological industries. Both are profitable economic ventures, competing for the business of people with epilepsy. The other type of competition was between indigenous and Christian treatments themselves. However, since this competition reduced opportunities for achieving a better quality of life for people with epilepsy, complementarity, rather than competition, is desirable.

Traditional treatments were ineffective, and in other cases costly but they were pursued nonetheless. The reasons given by participants for reliance on traditional treatments point to the strength of beliefs and the shortcomings of medical treatment (Jackson & Mupedziswa, 1988; Mutanana & Mutara, 2015). First, despite the shortcomings of traditional treatments, their social value and the power of traditional healers was still strong, one reason why medical interventions failed to change beliefs in traditional treatments (Jackson & Mupedziswa, 1988). The presence of evil spirits was well-embedded in the Zimbabwean psyche (Dube et al., 2011; Jackson & Mupedziswa, 1988; Kazembe, 2009, 2011; Madzokere, 1997; Mutanana & Mutara, 2015). Thus, identifying witches, who were purveyors of evil spirits, allowed the family to accord blame and find an outlet for their anger and possibly reduce stigma in the process. This could as well have reduced stigma attached to the family. Further, the survival of *Chivanhu* depended on people's persistent belief in the supernatural. Second, in the absence of psychosocial support services such as counselling and group work, religious and cultural gatherings closed the gap. Third, the lack of affordable and readily accessible medical treatment services meant traditional treatments were better option. However, the inefficacy of traditional treatments led to persistent seizures.

With appropriate medical treatment, seizure control facilitated improved educational, training, and job opportunities and greater acceptance in the workplace and wider community. Many of the participants had first learnt about medical treatment from the ESF in Harare but

most people with epilepsy in Zimbabwe were severely disadvantaged by the prevalence of ignorance about epilepsy and the absence of appropriate medical resources, especially in rural areas (Madzokere, 1997; Mielke & Madzokere, 2005; Mutanana & Mutara, 2015). On face value, it sounds like medical treatment was all what was needed to improve opportunities but the journey from the first seizure to getting medical treatment was very long due to beliefs and the absence of easily accessible and affordable treatment services as already discussed.

As already said, persistent use of traditional treatment resulted from a lack of affordable, accessible, quality healthcare and, most importantly, community education and awareness of epilepsy as an easily treatable neurological condition (Adamolekun & Meinardi, 1990; Baskind & Birbeck, 2005a; ILAE et al., 2000; Meinardi et al., 2001). In some instances, participants reported that health service providers like nurses, who well knew that epilepsy was a treatable condition, encouraged people to seek traditional treatments. On a broader level, failure to control seizures related to gaps in public services. Not only were policies inadequate, but services were poor and this impacted negatively on educational and employment opportunities for people with epilepsy. As said earlier, this represented maldistribution (Fraser, 2001, 2004, 2008; Taylor, 1994).

## *Ongoing gaps in public services*

### *Lack of educational and vocational support services*

Consistent with the literature, people with epilepsy reported lack of educational and vocational qualifications (Abidi & Sharma, 2014; Banks & Polack, 2015; Buckup, 2002; Échevin, 2013; Halima et al., 2017; ILO, 2007, 2013; Liao & Zhao, 2013; Schur, 2009; Wolffe et al., 2013a). Due to misinformation and stigma, the participants experienced barriers to education. Consequently, participants with childhood-onset epilepsy reported limited access to primary and secondary school education. Some had attended sporadically, while others had been forced

to drop out of school. Some teachers did not know about medical treatment or did not support it, and encouraged their students with epilepsy to seek favoured traditional interventions. Services to support vocational training were equally lacking. None of the participants had benefited from the government-run vocational training schemes, apprenticeships, cadetships, scholarships, and human-resource development. Service providers were critical of government rehabilitation services, such as Ruwa Rehabilitation Centre, near Harare, which offered medical rehabilitation and job-skills training. Its capacity was low, it was highly selective, and favoured people with physical disabilities.

It was clear from the experiences of participants that educational institutions did not have academic inclusion plans to meet the needs of people with epilepsy which should be standard practice in modern institutions of learning. Without these plans, people with disability fail to learn productively, at times they fail courses and this delays their completion. At the end, they fail not because they are not intelligent, but because enough attention is not given to the disadvantage they already have. Without plans to ensure inclusion, people with epilepsy were excluded from participation and did not enter the labour market as peers (Fraser, 2008, 2011).

## *Lack of public social welfare and disability services*

Not only were welfare and disability services not available but also accessing public services presented difficulties because the families of most participants were poor. Without extra assistance from the government, they could not meet their basic needs for health, education, and food, let alone gain employment skills or startup capital for informal enterprises. None of the participants was receiving social assistance from the government even though the Social Welfare Assistance Act (Government of Zimbabwe, 1988) and the Disabled Persons Act (Government of Zimbabwe, 1992) provided for monthly means-tested disability grants of USD20. Since these depended on the type and severity of the disability, people with epilepsy

were often excluded, as they did not have recognisable impairments. People with physical disabilities, such as those without sight and limbs, were more likely to be eligible for disability grants than those with hidden neurological and cognitive disabilities. Grants were a form of social security that helped reduce poverty and address the challenges that prevented people with disabilities from participating in the labour market (Banks & Polack, 2015; Buckup, 2002; ILO, 2004, 2006; Mitra, 2010; Mtetwa, 2011). However, it has been argued that, while welfare grants alleviated poverty in South Africa, they reduced employment-seeking behaviour and therefore failed to provide a long-term solution (Sung et al., 2014; Schneideret al., 2016). Service providers in this study confirmed that, without disability support, people with epilepsy found it difficult to provide for their basic health and education needs and, in most instances, their families could not provide for their skills training.

The service providers reported that the disability grant was supposed to be disbursed to district social welfare offices by the treasury on monthly or annually but most districts had not received funds for several years, confirming what previous researched termed a lack of political will in Zimbabwe (Choruma, 2007; Lang & Charowa, 2007; Marongwe & Mate, 2007; SINTEF, 2003). The country's economic difficulties notwithstanding, welfare clients in receipt of other welfare grants were receiving regular payments. War veterans were a case in point. They included those who had fought in the war of liberation that had ended with Zimbabwe's independence in 1980. They were receiving USD360 monthly for welfare support, 18 times more than recipients on disability grants. Clearly, there were strong political factors at work here, since this constituted the ruling government's power base. Seen through Fraser's lens of social justice, people with epilepsy lacked recognition and representation, i.e., social and political power respectively. Not only was the disability payment abysmally low at USD20 monthly, but the means test excluded most people with epilepsy. To promote employment creation for disadvantaged groups, the Zimbabwean government distributed USD500 annually

to districts for developmental projects, such as small enterprise development. This could do little given most districts comprised about 200,000 people and monies for individual and group support was rarely made available or would be diverted to other uses or simply misused by government officials.

Clearly, the government was not resourcing local or nationwide awareness initiatives and was not prioritising disability in the allocation of national resources, as shown by the non-availability of public social assistance for participants in this study. Instead, the government prioritised the politically expedient war veterans' pension. In Fraser's (2003) terms, this constituted a maldistribution of public resources, which was rampant in Zimbabwe, fueled by corruption and the mismanagement of public resources (Transparency International Zimbabwe, 2015).

Service providers and participants agreed that epilepsy was neglected both as a disability and chronic health condition. They recommended that the Disabled Persons Act (Government of Zimbabwe, 1992) should recognise epilepsy as a disability to ensure the inclusion of people with epilepsy in government programs. However, not all people with epilepsy experienced disabilities, especially where epilepsy was treated and reasonable accommodations achieved. To that end, it was important that disability legislation recognised all impairments, including epilepsy, based on a clear definition of the type of limitations that constitute a disability.

Disability services lacked a central case-management system so welfare services were divorced from employment support, yet success hinged on collaboration between service providers. The National Disability Board, which ran the National Disability Fund, had no dedicated staff and depended on Department of Social Welfare officials, who were overwhelmed with other duties. Literature persistently showed that employment support was

an important pillar that promoted successful employment outcomes for people with epilepsy (Buckup, 2009; ILO, 2016; Soeker et al., 2012; Yuh et al 2013).

## *Medical health services were expensive and difficult to access*

Health services were of poor quality and expensive, therefore, beyond reach for most participants in this study. Consistent with findings from two studies in Malawi and many other African countries, people with epilepsy in Zimbabwe delayed treatment by several years (Baskind & Birbeck, 2005a; Elger & Schmidt, 2008; Mushi et al, 2011; Watts, 1989, 1992; WHO, 2016). Medicines and vital medical services were often not available and, when they were, were expensive. Though public health services were available in urban areas, their quality was erratic. Hospitals were overcrowded and under resourced and the community health workforce lacked the capacity to complement hospital-based treatment or to educate communities about epilepsy and the ease with which it could be treated, if properly understood 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 pointed out that nurses were not appropriately trained to manage epilepsy yet patients were attended to by nurses most of the time. Many a time, nurses waited for doctors to diagnose and initiate treatment for epilepsy, increasing the time patients had to wait before they got initial medical treatment. Issues of poor health services and inadequately trained nurses have been reported in previous studies in Zimbabwe and other African countries (Baskind & Birbeck, 2005a; Duggan, 2013; Mushi et al, 2011; Saburi et al., 2006).

## *Reliance on nongovernment support services*

As already mentioned, all participants had received nongovernment services, including counselling, treatment, information, training, and (limited) employment support services from the ESF. Service providers at the ESF indicated that resource-strapped NGOs had assumed

several roles usually filled by government services. They highlighted that, given more nurses, social workers, and community workers, the ESF could provide treatment for more people with epilepsy and improve the quality of life of those already on treatment. However, the consensus was that the organisation was too small to cover the whole nation. Hence, the provision of public services to people with epilepsy remained a public-sector duty that government should prioritise. It was clear from the focus group discussion that service providers did not have the requisite skills to provide effective, planned, long-term employment services. Literature shows that that nongovernment organisations played an important role in improving quality of life of people with epilepsy, together with reliable public services (2015; Jacoby & Baker, 2008; WHO, 2016).

### *Challenging job-seeking and workplace environment*

#### *Job-seeking challenges*

Three main factors made job-seeking challenging – lack of vocational skills, uncontrolled seizures, and competition for limited job opportunities. With seizures, job seekers with epilepsy could not easily hide their condition. Once noticed and labelled, they would not easily find employment. Their job networks dwindled and having qualifications carried little weight once it was known they had epilepsy. However, some with controlled seizures lacked appropriate vocational training, and did not have the requisite work skills required by employers. This made it very difficult for them to succeed in a highly competitive job market. When jobs were available, these were undesirable and characterised by low pay, again a form of injustice (Fraser, 2008).

As in many countries in the Global South, there was a lack of employment opportunities and no employment quota system for people with disability, just like in Zimbabwe. Literature shows that reserving positions for people with disabilities reduced barriers to employment

(Abidi & Sharma, 2014; Échevin, 2013; ILO, 2005; Schur et al., 2009). The Zimbabwean government's policy on equalisation of opportunities for people with disability in the public sector only supported those already in public employment and did not cover those in private employment (Government of Zimbabwe, 2011). South Africa offered an example: its government had reserved 2% of jobs in the public service for people with disabilities (Gathiram, 2008). This figure, though low, given that 15% of employees were expected to have disabilities, was at least a starting point.

There was no doubt Zimbabwe's economic decline that had seen many companies closing, scaling back, or migrating to other countries, could account for the lack of job opportunities but this did not explain the exclusion of people with epilepsy from the same market that accommodated their peers and siblings. Official government statistics reported an unemployment rate of 11%, when the majority of the economically active population was 'employed' in the informal agriculture and trade (Government of Zimbabwe, 2012). For people with epilepsy, penetrating this informal job market was equally difficult, due to negative attitudes and lack of skills or capital to start informal businesses. For those with formal jobs, persistent barriers made their employment situation tenuous; many were in jobs where their skills were underused meaning they were unproductively employed.

*Persistent barriers in the workplace*

Not only had participants faced barriers to treatment and education, due to negative social attitudes but also in the workplace, where persistent misinformation about epilepsy generated fear and affected their relations with co-workers, managers, and customers, as the case might be. In the workplace, people believed epilepsy was contagious. There were persistent beliefs that employees with epilepsy were incompetent; employees would leave if they knew a co-worker had epilepsy; customers would be lost; or, at the extreme, the person with epilepsy would die on the job. These persistent beliefs, negative attitudes, and resultant fears made it

205

difficult for people with epilepsy to maintain their employment; curtailed their productivity; affected them psychologically resulting in mental health issues and, in some cases, seizures; compromised their earning potential and promotional prospects; led to unfair dismissals; and prevented access to pension and medical aid despite the tenuousness of their employment and retention issues. This confirmed earlier findings pointing to the reluctance of employers to hire people with disability (Bishop, 2002; Buckup, 2002; Halima et al., 2017; Hlatywayo et al., 2014; Hounsossou et al., 2015; Wiggett-Barnard & Swartz, 2012). This reluctance persisted, despite studies showing the benefits of, and dispelling negative stereotypes about, employing people with epilepsy (Banks & Polack, 2015; Bishop, 2002; Buckup, 2009; ILO, 2016; Jacoby & Baker, 2008; Jacoby et al., 2005; van Niekerk, 2010; Wolffe et al., 2013a, 2013b). However, on a positive note, past experiences of working with people with epilepsy had enhanced employers' willingness to hire and retain them in the same manner reported by Ju et al. (2013) and Jacoby et al. (2005).

Workplace policies and employer networks to create a receptive environment for hiring and retention were non-existent in Zimbabwean workplaces, yet these were found to be facilitators of employment in an earlier study by Erickson et al. (2014) and Jacoby et al. (2005). This showed that the presence of labour laws, such as the Labour Act (Government of Zimbabwe, 2005), did not guarantee nondiscrimination and fair labour practices. The law was useful only where employers believed people with epilepsy were equal to other employees and that they could work productively. Some employers did not seem to think that it was unfair to dismiss people with epilepsy from work. The same could be said of labour unions, yet they should recognise and protect those facing discrimination, including working women. Employers did not consider this burden, making the needs of women with epilepsy misrecognised (Fraser, 2008, 2011; Honneth, 1997).

## Gender issues in the workplace

Women reported more burdensome experiences in employment, but there were no discernible gender differences in other experiences like education and job-seeking. Working women with epilepsy reported a 'triple burden' as income earners, mothers and wives, and people living with a disabling chronic condition. This burden increased their risk of dismissal at work, as Mucha's case study clearly demonstrated. Further, in traditional Zimbabwean society, women were expected to take on caring roles in the family and to enter caring professions, such as teaching or nursing (Chifamba, 2015; Peta et al., 2015; Shoko, 2013). This had changed little with the shift to women playing a more active role in the labour market. Despite calls for national and workplace policies that recognised the roles of women and addressed the disadvantages they might face in securing and maintaining employment (Buckup, 2009; ILO, 2016), women in Zimbabwe still faced more barriers than men in the labour market (Chifamba, 2015; Choruma, 2007; Madzokere, 1997; Murimi, 2013; Peta et al., 2015). The situation might become unbearable for them, especially considering the absence of employment support services reported in this study. Women with disability were also disadvantaged in other countries (Banks & Polack, 2015; Buckup, 2002). Fraser and other social justice theorists viewed this as misrecognition that prevented women to participate as peers (Danermark & Coniavitis, 2004; Fraser, 2001, 2008; Honneth, 1997; Knight, 2015; McNay, 2008).

## Absence of employment services

The social interventions to support employment described in the literature, including occupational services (ILO, 2001, 2015; Soeker et al., 2012), were not available for most participants in this study, neither were there any dedicated government disability employment service. Reports from the department showed that it was severely understaffed, employment officers were overwhelmed with work, and there were no disability-specific services. The ESF

and other nongovernment organisations did not have specific employment services. Studies have shown that economic problems were among the most reported challenges of people with epilepsy (Mugumbate & Nyanguru, 2013) and other disabilities (Cramm et al., 2013, 2014), yet income support services too were lacking for the participants of this study. Previous studies showed that services to support employment reduced barriers for people with disabilities (Banks & Polack, 2015; ILO, 2005; Yuh et al., 2013).

Service providers were not aware of targeted disability schemes run by the Public Service Commission, which recruited government personnel. However, the Commission had a policy to equalise opportunities in the public service which was supposed to be overseen by disability-focused persons in various government departments. The policy ostensibly sought to reduce discrimination for those already in employment and, to a lesser extent, those seeking employment but it had no specific objectives to improve the work skills of jobless people with disabilities. Affirmative action policies might increase access to the recruitment of people with epilepsy but government first needed to ensure the basic human right to education, work, and earning a liveable wage was entrenched in its policies and services. Earlier studies found that affirmative action facilitated employment (Banks & Polack, 2015; Maja et al., 2011; Marumoagae, 2012; Mizunoya & Mitra, 2013; van Niekerk, 2008).

*Lack of recourse to justice in the workplace*

Despite human rights and labour laws to reduce discrimination and provide policy measures to increase the inclusion of people with disability in the labour market, people with epilepsy remained excluded. In this study, participants were unable to challenge their dismissals or other experiences of discrimination in court. Existing legal channels, such as they were, were expensive with limited chances of success due to the policy environment and negative social attitudes toward people with epilepsy. Effectively, therefore, they had no recourse to justice following unfair dismissals related to seizures in the workplace. For example, while the Labour

Court of Zimbabwe was a sound institution, it was not useful because people with epilepsy required huge sums of money to hire lawyers to help them navigate the complex legal system. If they did not hire lawyers, the employers they were challenging would do so, making their legal efforts futile. It took a long time before cases were heard and before judgements were delivered although the Disabled Persons Act (Government of Zimbabwe, 1992) had anti-discrimination clauses, no case had been brought to court indicating that those facing discrimination suffered in silence, as did the participants in this study.

The years wasted on trying to access education, appropriate medical treatment, and employment would be the subject of lawsuits in the Global North but, in Zimbabwe, people's expectations of the government had reached an all-time low, due to years of misrecognition of people with disabilities (Honneth, 1997). Not only did the treatment of people with epilepsy in the workplace constitute a violation of their basic human right to work and earn an income, but the lack of recognition and representation for people with disabilities in Zimbabwean society meant an absence of advocacy. Without a strong, collective service-user voice, social injustices persisted (Danermark & Coniavitis, 2004; Fraser, 2001). Without strong advocacy for human rights and social justice, the government was unlikely to reorganise labour and develop effective labour-market policies accommodating diverse groups in Zimbabwean society. More particularly, it was unlikely to ensure mechanisms were in place to ensure recourse to justice in the face of unfair work practices and wrongful dismissal. The dire economic situation in Zimbabwe did little to improve educational, health, employment, welfare, and legal services. Public service failures resulted in people with epilepsy resorting to self-management to overcome barriers to employment.

## *Self-management and individual factors*

This study found an individualistic service ethos, where individuals had to solve their own problems and where problems were treated on a case-by-case basis. Due to the failure of public

support systems and the individualistic service ethos, participants had become self-reliant and resilient, however, some became vulnerable. This argument has been raised before by other researchers (Dewa et al., 2014; Lindsay & Fleeman, 2016; Munn, 2008; Richardson, 2002; Sebit & Mielke, 2005). Several individual factors made this possible.

*Self-management, resilience, and vulnerability*

The findings of this study pointed to a sequence of barriers culminating in poor employment outcomes for people with epilepsy, including fear, stigma, and exclusion. This was compounded by poor public services. Hence the chances of attaining or maintaining employment were reduced. In the words of Service provider 5, success was 'by force or by God's grace'. This resulted in people with epilepsy having to deal with their seizures and socioeconomic injustices. With no reliable public services, people with epilepsy were left to manage their adversity themselves. Some were resilient and succeeded but others became more vulnerable, as had been reported in prior studies (Dewa et al., 2014; Jacoby & Baker, 2008; Munn, 2008; Richardson, 2002; Sebit & Mielke, 2005). Some participants adopted a fighting spirit, while others simply gave up.

Resilient individuals accepted their condition and maintained a positive attitude and had a mastery of epilepsy. They had supportive families and employers. This confirmed prior studies on the importance of support systems in building resilience (Elliott & Shneker, 2008; Ring et al., 2016). Elliott and Shneker (2008) found that health workers who formed part of these support systems lacked correct knowledge about epilepsy. The participants of this study were positive about the ESF and the service providers believed in the importance of support groups, public education, and advocacy work. In other rare cases, participants such as Munya reported that their employers were supportive, although co-workers were not. Previous research by Jacoby et al. (2005) concluded that some employers were willing to accommodate people

with epilepsy. Factors that promoted this positive attitude were having employed people with epilepsy previously, correct knowledge of epilepsy and having disability support services.

Vulnerability was exacerbated by continuous negative attitudes towards people with epilepsy. Without supportive policies and programs, vulnerable participants failed to overcome the vast socioeconomic challenges they faced or to secure timely medical treatment. Though interventions focused on individuals, prior studies confirmed that individual vulnerability was related to external factors, such as access to essential resources and services and economic opportunities (Ring et al., 2016). Participants in this study, such as Munya, Hadeel, and Derry, had resorted to informal employment, even though it was not rewarding and they lacked the finances to engage fully in productive informal work. Others sought work in neighbouring countries following their failure to secure work in the formal labour market. Their persistence attested their resilience

A mastery of epilepsy and good seizure control were found to be good facilitators of employment in this study confirming previous findings (Al-Adawi et al., 2003; Coker et al., 2011; Elliott & Shneker, 2008; Ring et al., 2016; Taylor et al., 2011). In this study, seizure control depended on family beliefs, knowledge of epilepsy, and treatment accessibility. Unreliable health services led to restricted employment chances for people with epilepsy, as found in other studies (Sebit & Mielke, 2005). This study showed that employment challenges for people with epilepsy were multifaceted and required diverse interventions and supports, as Taylor et al. (2011) reported. In the absence of such supports, individual resilience and self-management became pivotal to coping but were unlikely to offer a total solution for the massive sociostructural, cultural, and economic problems impacting on the lives of people with epilepsy in Zimbabwe. Clearly, individual resilience and self-management were coping mechanism but were unlikely to offer a total solution to the problems of people with epilepsy in Zimbabwe.

People could cope with social support, but the most important factor in living a quality life was the independence that came with gainful employment.

*Individual factors*

While the study focused on structural factors impacting employment of people with epilepsy, the experiences showed individual attributes had an influence too. Literature showed that these included mastery of epilepsy, age; seizure onset, type and control; marital status; geographical location; economic status; wellbeing; and intelligence (Al-Adawi et al., 2003; Coker et al., 2011; Elliott & Shneker, 2008; Tai, 2011; Wo et al., 2016). Some of these were applicable to participants in this study, as already discussed but they are highlighted again here.

Since most participants (n=18) had child-onset epilepsy, their parents had arranged their treatment, which increased the likelihood of traditional treatment as the first port of call, due to its cultural embeddedness and social acceptability. This was compounded by the cost and lack of availability of biomedical treatment, as highlighted by the service providers. The fact that 16 participants were not in formal employment and all participants did not have an adequate income to acquire services, attests the importance of socioeconomic status in treatment choice. Further, there was evidence that more educated participants had achieved greater mastery over their epilepsy than less educated participants. Though it was difficult to determine whether rural backgrounds had influenced participants' experiences in this study, it might be surmised that growing up in a rural area would predispose people with epilepsy to traditional treatments that were more prevalent in rural than urban populations in Africa because service quality was erratic (Baskind & Birbeck, 2005b; Watts 1989, 1992). The over reliance on traditional treatments was also linked to low economic status of participants since traditional treatment was more accessible than fee-based medical tests.

### *Effective strategies*

Participants suggested several strategies to improve the employment of people with epilepsy. The strategies were informed by the biopsychosocial, social and human rights model of disability with limited focus on economic issues. They stressed the role of education, training, government and nongovernment services. However, their suggestions focused on services to individual on a case-by-case basis, though other suggestions highlighted the need for taking a structural approach advanced by Fraser (2001, 2004, 2008). Another limitation of the suggestions was a neglect of the private sector. As suggested by WHO (2016) and ILO (Hlatywayo et al., 2014; ILOb, 2008, 2015), the private sector plays an important role in the delivery of employment services. ILO (2015) recommended inclusion of awareness of disability issues to private sector employees. Hlatywayo et al. (2014) recommended incentives to the private sector to employ people with disability. The suggestions made by participants are discussed in turn.

### *Epilepsy education*

Participants gave suggestions for epilepsy awareness, including borrowing from the HIV and AIDS model which was successfully used to end AIDS related stigma. Epilepsy education was required to reduce stigma and to promote uptake or early medical treatment (Birbeck, 2000; Mushi et al 2011; Watts, 1989; WHO, 2015). Literature showed that epilepsy stigma can be enacted and felt and could be experienced by families and co-workers too (Baskind & Birbeck, 2005a; Halima et al., 2017; Kilinc & Campbell, 2009; Obeid, 2008). However, epilepsy stigma looks more complex than HIV related stigma in that it is embedded in society as opposed to HIV stigma which was a new phenomenon. As this study showed, public awareness of epilepsy as a treatable condition increased treatment uptake, yet resources for nationwide awareness

initiatives were nonexistent, and government had not prioritised epilepsy in the allocation of public resources.

*Government services*

Government services focused on individual issues and did not take a structural approach. Even interview participants were more concerned with availability of social welfare grant and reserved jobs than policies to ensure sustainable social assistance and make government more accountable. Some service providers supported this direction. A missing suggestion was on having employment services provided by government to people with disability such as epilepsy yet literature shows this was important (Banks & Polack, 2015;, 2015; Mhiribidi, 2010; Mitra, 2008, Mupedziswa, 2001; Mupedziswa & Kubanga, 2010, 2016). Failure to provide employment services for people with disability is not only costly to them and their families, but also their community and country (Banks & Polack, 2015; ILO, 2007, 2015). Though Zimbabwe has a strong infrastructure of public health services in urban areas, service quality is erratic, and hospitals are overcrowded and under resourced. Reliable private services, though available, are expensive and out of the reach of most Zimbabweans. Lacking is a strong community health workforce educating communities about the ease with which epilepsy might be treated if properly understood as a neurological condition. The suggestion by service providers for government to fully implement international and regional protocols on disability were important. Social justice is a global issue that requires global cooperation (Fraser, 2011 Hölscher, 2014).

*Nongovernment services*

A few of the participants like Sanga talked about representation of people with disability in policy making structures such as parliament. While the ESF had joined the disability movement and had advocacy officers, its work was still lacking in this regard. Other groups of people with

214

epilepsy were still not well represented, especially those in employment and those staying in rural communities. People with epilepsy in this study had received treatment and social support from the ESF in Harare but most people living with epilepsy in Zimbabwe are severely disadvantaged by the prevalence of ignorance and absence of appropriate resources, especially in rural areas (Duggan, 2013; Ferguson, 2012; Halima et al., 2017; Mushi et al., 2011; Nuhu et al., 2010). The dire economic situation in Zimbabwe did little to improve the situation.

The fact that the ESF had taken both a biopsychosocial model approach through the provision on health services and a social model through disability advocacy was commendable. The focus on epilepsy as a health condition, which is presently the dominant strategy in Zimbabwe, neglects the structural issues surrounding the condition, including the cultural impediments. Taking epilepsy as a disability is viable option, though once fully treated, it could cease to be a physical disability. The viability rests in the point that Zimbabwe has a disability movement that has potential to advocate for better services, especially the removal of stigma. So, the disability option allows for structural impediments to social, economic and political advancement to be addressed wholesomely, in line with Fraser's social justice theory (Danermark & Coniavitis, 2004; Fraser, 2004, 2008; Honneth, 1997). But for epilepsy, medical treatment is crucial, hence a balance is required between medical and social goals.

*Individual management*

Participants recommended improving individual ability to manage epilepsy and to look for jobs. Despite the odds stacked against them, the findings showed that eight participants had demonstrated remarkable resilience by overcoming chronic unemployment. As pointed out by service providers, in the absence of reliable public services, people with epilepsy were left to self-manage their adversity. This confirms findings from other studies (Bradley et al., 2016; Day, 2008; Edward et al., 2015; Ring et al., 2016; Taylor et al., 2011). Faced with numerous barriers, individual resilience acted as a strong coping mechanism that resulted in better

employment outcomes for a few participants. Resilience was an individual psychological attribute but other individual factors like seizure type and age that impacted employment of people with epilepsy in several ways, but these were not fully explored in this study although the literature covered these extensively (Wo et al., 2016). These could be gaps for future research in Zimbabwe. However, relying on individual management was only a coping mechanism that should not stop service providers and service users from advocating for government-provided employment services to achieve social justice.

A major problem for people with epilepsy in Zimbabwe was their lack of representation in policy-making structures. People with epilepsy lacked a voice and concurred with service providers that a rights-based approach was needed to ensure social justice for people with epilepsy. Such an approach would enhance access to productive employment supported by policies and services to ensure fair treatment for, and prevent unfair dismissal of, people with epilepsy in the workplace. Representation would extend to policy-making structures within the workplace, as well as in broader policy networks. Recognition would guarantee social assistance for people with epilepsy to gain an education and access work, supported by accessible medical, health, education, and social support services, in line with ILO's (2007, 2015) recommendations on the employment of people with disability.

## Conclusions

The main conclusions drawn from the study's findings were:

1. There was persistent misunderstanding of epilepsy resulting in:

   a. Negative social attitudes, practices, and stigma that were major barriers to employment for people with epilepsy.

b. People with epilepsy not getting adequate medical treatment on time and this had negative impacts on their socialisation, education, training, and employment.

c. Workplaces that were unfavourable to people with epilepsy seeking employment or already working due to negative attitudes of employers and co-workers.

2. There were inadequate government policies and public services:

a. To reduce the economic and social disadvantages for people with epilepsy, decreasing their employment prospects.

b. Leading to an individualistic service ethos that further exposed people with epilepsy, rendering those with self-management skills more resilient and those without these abilities vulnerable to further disadvantage.

These conclusions are discussed in turn.

### *Persistent misunderstanding of epilepsy*

### *Negative social attitudes, practices, and stigma were a major barrier to employment for people with epilepsy*

Ignorance and misconceptions about epilepsy were a huge barrier to social inclusion for people with epilepsy in this study. Despite public education and awareness programs, cultural and religious beliefs remained remarkably impervious to change. The reasons for this were found to be complex but related mostly to the ease of availability of cultural and religious treatments, and their social desirability and affordability. In a country in economic decline, where formal health services had dropped below world standards and were not easily accessible, people tended to fall back on local and traditional networks and the comfort of their sociocultural

milieu. Living with epilepsy was difficult enough for the subjects of this study without the added tension of going against community norms.

*Untreated epilepsy impacted negatively on education, training, and employment*

Uncontrolled epileptic seizures increased the 'noticeability' of epilepsy, resulting in increased fear and isolation of people with epilepsy in the family, community, school, and workplace. This, in turn, resulted in limited social, educational, and employment skills, yet these were prerequisites for positive employment outcomes. In the community, people with epilepsy had limited social contacts and poor job networks. Primary and secondary education, which formed the basis for vocational education, was affected resulting in low or no employment skills. This reduced their chances of acquiring jobs.

*The workplace was unfavourable to people with epilepsy seeking employment or already working*

In the workplace, people with epilepsy found themselves faced with employers, managers, and co-workers who had little understanding of their condition and harboured the same myths and misconceptions they encountered in their communities. This was a hindrance to getting and maintaining work, and working productively.

### *Poor public policies and services*

*Poor public policies and services failed to reduce barriers to employment*

Despite adherence to international treaties and charters on the rights of people with disabilities and existing national disability, social welfare, and health legislation, people with epilepsy in Zimbabwe continued to be denied their basic human rights and access to social justice due to poor public policies and services. There appeared to be no mechanisms in place to ensure

enforcement of existing legislation in Zimbabwe. Poor, inadequate, and inaccessible public services exacerbated an already existing handicap of epilepsy and acted as another barrier to employment. Further, there were no employment services to enhance the participation of people with epilepsy in the Zimbabwean economy.

*Individualistic service ethos further reduced employment opportunities for people with epilepsy, resulting in self-management strategies*

Despite the barriers encountered in their journey towards gaining a liveable wage, some of the participants of this study demonstrated tremendous individual resilience that enabled them to overcome some of the challenges. They exhibited a strong fighting spirit in seemingly hopeless situations, including an economy with few employment prospects and ongoing shame associated with their condition. Several factors made this possible, including strong family support to enhance individual resilience. A strong factor was their ability to manage their situation themselves to reduce barriers to employment by pursuing and completing vocational training; challenging negative social attitudes and cultural practices; and monitoring their treatment and managing its side effects. However, the provision of public services to people with epilepsy remained a public-sector duty that government should prioritise.

These conclusions have several implications for social policy and social work. Given Fraser's (Fraser, 2001; Fraser et al., 2004) framework of social justice undergirding this study, the main implications are that redistribution, recognition, and representation are needed to break down barriers to employment for people with epilepsy in Zimbabwe. This framework has potential to impact positively on policies, services, and service-provider education, as discussed below.

## Implications of the findings

### *Implications for social policy*

#### *Suggested policies*

Four policies are suggested, in the first instance. These are:

1. National Epilepsy Policy

2. National Disability Policy

3. Amended Disabled Persons Act

4. Disability Inclusion Policies

A National Epilepsy Policy would tie together fragmented epilepsy services in Zimbabwe. As discussed earlier in this thesis, there is no specific policy to deal with epilepsy in Zimbabwe. The National Epilepsy Policy would espouse medical and social objectives of accessible and affordable medical treatment. The Policy would enhance its function by providing for a National Coordinator for Epilepsy Services and by having a budgetary allocation for epilepsy affairs. The WHO resolution on epilepsy just adopted in 2015, offers the best framework and opportunity for a national policy on epilepsy. In the absence of a dedicated epilepsy policy, another option would be to ensure that epilepsy were addressed effectively in: (i) chronic disease health policies to guarantee the medical services required; and (ii) disability and social development policies to reduce stigma and disadvantage. However, the shortcoming of this alternative policy would be that epilepsy would not receive adequate attention.

The Disabled Persons Act (Government of Zimbabwe, 1992) needs revision. A comprehensive People with Disability Act is needed to move from a remedial welfare model to a developmental approach providing proactive opportunities for the employment of people with disabilities in line with the CRPD (UN, 2006a), which Zimbabwe ratified in 2013. The

starting point would be a People with Disability Bill spearheaded by the disability board and Parliamentary Senators or DPOs representing people with disabilities.

The National Disability Policy would start from the extant draft. The policy would close the gap between the Act and practice. This would ensure that the new Act did not become another non-starter, that is, a policy without adequate implementation. However, the proposed provisions of the National Disability Policy could still be placed within the new Disabled Persons Act. The disability board, as mandated by government, should monitor the implementation of disability law through various strategies, such as certifying public and private employers with disability inclusion plans, and holding annual disability and employment conferences for employers, people with disabilities, government agents, researchers, trainers, service providers, and representatives of DPOs.

Disability inclusion policies are required urgently for private, public and nongovernment institutions including (i) schools (ii) traditional and religious institutions (iii) tertiary training institutions (iv) employers and (v) government institutions like courts. The policies would state clearly how the institution understands disability, opportunities available to people with disabilities, channels for complaints and communication and accommodations made or planned for the future. Public and private institutions providing services that would enhance employment of people with disabilities, such as schools, colleges, universities, apprenticeships, employment agencies, and others should be encouraged to have in place disability inclusion plans of their own spelling out how they would provide access to their services. Other initiatives could include a fund set aside for promoting accommodation and a disability-focused network of employers.

Implementation plans from these policies would need to specify budgetary requirements to ensure that adequate medical services were provided and that the barriers to full participation were reduced in line with all aspects of disability.

## Cultural and behaviour change

Current cultural epilepsy narratives misrecognise the condition. To combat stigma and other negative social attitudes resulting from the current narrative, public epilepsy education is needed to overcome negative social attitudes towards epilepsy. This would bring much needed change of outmoded cultural practices in Zimbabwean society. Continuous long-term education and awareness is required to deal with ignorance surrounding epilepsy. To mount a successful awareness strategy, lessons could be drawn from the successful HIV and AIDS campaign as described by participants. The HIV and AIDS model had political support and was adequately funded to the extent that within a few years AIDS related stigma was curtailed. The behaviour change campaign for HIV was aligned to effective free treatments and community based health fronted by village health workers. Opportunities for awareness exist in:

1. International Epilepsy Day
2. National Epilepsy Awareness Week
3. Community based care system
4. International Day of People with Disability
5. World Mental Health Day

## Resourcing and funding

Government must fund:

1. Free first-line and second-line drugs and treatments
2. Free education and vocational training
3. A public Disability Employment Agency
4. Upskilling of service providers and training and retention of specialists like neurologists

Resources should be made available for free first-line and second-line medical treatment to ensure early control of seizures within supportive health services, just as in the case of HIV and AIDS. Third-line medicines and specialist services need to be available and affordable. Primary healthcare clinics must stock adequate quantities of first-line drugs. Nurses at primary health centres must be able to diagnose epilepsy and initiate treatment without having to wait for doctors to do this. Treatment plans for people with epilepsy must embrace health and psychosocial objectives. Nurses must be enabled, through training, to refer people with epilepsy to service providers, such as occupational therapists, social workers, and employment officers. A huge gap that should be urgently addressed is the lack of a single neurologist in Zimbabwe.

Free basic education and training is required to enhance social inclusion. Children with epilepsy should have access to compulsory basic education from preschool to high school and teachers should be trained to manage children with epilepsy in the classroom and the school environment. Parents need support to be able to keep their children in school, including assistance with school and medical fees and community education programs. Community education increases the acceptance of children in school and the community. Basic school education curriculum content should support the vocational aspirations of children with disabilities. The National Employment Services department must be expanded to have a dedicated recruitment agency for people with disabilities, which should engage in career guidance at primary and secondary schools, and provide post-secondary school work placement support.

A public Disability Employment Agency to foster secondary school-to-work, college-to-work and welfare-to-work programs is required. People with epilepsy must be supported to enable them to reduce the barriers to finding employment. While a dedicated epilepsy employment agency is unlikely, a Disability Employment Agency for Zimbabwe is desirable.

The agency could be a public entity, run by the disability board while private and nongovernment players could play complementary roles. However, for those who are unable to move into formal or informal work, government must play its key role in social protection through just distribution of state resources, especially social assistance to people with epilepsy and their families to ensure that they are enabled to participate in society as peers, that is, on an equal basis with others (Fraser, 2001).

Service provider capacity building to ensure quality service provision is urgently needed. This is particularly so for neurologists because there was none in Zimbabwe when this study was done yet they are important for cases that require specialist treatment. Service providers in this study were aware of government-run employment support initiatives to help people with disabilities but did not have adequate knowledge about these. This pointed to an information gap that prevented service providers from helping people with epilepsy access services and initiatives that could be beneficial for them.

One question that would arise is the funding of disability and employment programs suggested in this research. Existing channels could be enhanced, including the Disabled Persons Fund (DPF), which would require additional funding for education and employment services. Currently, funding comes from the national budget but is limited because there seem to be few push factors for MPs, the Ministry of Labour, disability board, and people with disabilities to lobby for a bigger budget. Increasing the budgetary allocation to the DPF would be the main source of funding but another avenue of funding could be the ZIMDEF which collects a levy from employers to fund skills development in Zimbabwe. About 15% (in line with current disability estimates internationally) of this fund could be reserved for people with disabilities and channelled to the DPF. The AIDS Fund, which is levied from employers and employees, provides a good model of a successful scheme. Since its inception, the AIDS Fund has provided sustainable sources of funding for HIV programs in Zimbabwe focused on

financing awareness, behaviour change, personnel, research, and anti-retroviral medicines. The same could be done to establish a sustainable fund for disability services in Zimbabwe. With political will, these suggestions are easily implementable.

## *Enhancing representation*

DPO capacity building to ensure a vibrant movement to advocate for rights of people with disabilities is desirable. In situations, such as those in Zimbabwe, where government has failed to expand public services for people with disabilities, funding for organisations of people with epilepsy, such as the ESF, should be provided. Institutions dealing with employment, such as the Employers Confederation of Zimbabwe, and trade unions have not heretofore played a role in improving employment opportunities and conditions of people with epilepsy and they could do that by having people with disability represented in their structures. Hence a Disabled People's Labour Union might be an appropriate mechanism to enhance the voice and promote the interests of people with disabilities in Zimbabwe, with organisations such as the ESF expanding their services to play an important role in advocating for people with epilepsy in employment.

## *Improving coordination*

Presently, services that would enhance employment for people with disabilities are fragmented and largely lack long-term planning. There could be several strategies to deal with this, such as:

1. Centralised case management under the Ministry of Social Services.
2. Staff for disability board
3. Annual National Disability and Employment Conference.
4. Website dedicated to disability affairs.

Ideally, the proposed new laws could provide for a secretariat with trained disability case managers under the disability board. An ideal situation would be having case workers, officers or managers for people with disabilities, who will open case files for those receiving services from the Department of Social Services as well as those receiving support under the Disability Fund. At the end, the officials would convene case conferences to improve coordination of their services. The challenge with this system would be that the departments are understaffed to the extent that they system may not work fully in rural areas, and perhaps not appropriately trained in case management. An Annual National Disability and Employment Conference is desirable to bring together service providers, people with disabilities, employers, policy makers, researchers and educators to deliberate on issues that could improve income for people with disabilities and increase their contribution to national income. The disability board could lead the conference with support of the private sector. Online services provide opportunities for disability awareness and sharing information on laws, programs, disabilities, and research. Yet, disability services in Zimbabwe remain offline.

## *Suggested epilepsy-management model*

Previous models, for example, Watts' (1989), the African Declaration on Epilepsy, and Global Campaign Against Epilepsy, focused on the medical nature of epilepsy. They failed to balance the medical and social needs of people with epilepsy, let alone the economic. They largely looked at epilepsy as an individual issue neglecting the systemic issues that disadvantage people with epilepsy. Here, a model is proposed that addresses these shortcomings, building on the positive aspects of previous models, as shown in Table 9.2.

## Table 9.2: Comprehensive epilepsy-management model

| Key aspects | Barriers to participation | Main requirements |
|---|---|---|
| Economic redistribution | Medical | Adequate supply of free drugs and epilepsy management services. |
| | Misunderstanding | Adequate health education and promotion through publicity about the availability of treatment. |
| | Resources/funds | Policies to ensure funding is guaranteed. |
| | Lack of income | Accessible employment services and opportunities and social welfare support. |
| Cultural recognition | Beliefs | Educate employers, educators and stakeholders in employment about epilepsy. Provision of accurate information about epilepsy to change how culture represents epilepsy. |
| | Traditional treatments | Regulation and improvement of traditional treatments. |
| | Status recognition | Recognise the disabling nature of epilepsy and that people with epilepsy form a disadvantaged group especially women, workers and rural people with epilepsy. Targeted epilepsy anti-stigma and anti-discrimination legislation. |
| Political representation | Policy | Targeted national epilepsy legislation and management plans e.g. employment policy, disability policy, health policy. Domestication of regional and international instruments. |
| | Self-representation | Self-representation through support growth organisations and initiatives supporting people with epilepsy to build their sense of self. Ensure representation in all sectors including workplace boards, education boards. |
| | Justice | Easy access to courts. Clear formal processes to challenge injustice. |

The proposed model emphasises the economic, cultural, and political aspects of epilepsy. The model could be used by service providers and people with epilepsy as a tool to plan or evaluate epilepsy programs. Programs that recognise that challenges facing people with

epilepsy are economic, sociocultural and political in nature are likely to address the key challenges faced by people with epilepsy.

Key aspects of the model are economic redistribution, cultural recognition, and political representation. The key aspects are broken down into barriers, and requirements to address these barriers. The barriers encompass income, medical aspects, misunderstanding, policy, participation and justice. The model acknowledges the key role of biomedical treatment in the control of seizures, but emphasises that ending seizures cannot be the end of managing the condition, there is need for economic support to ensure access to medicines, and social support to ensure that the stigma of having epilepsy does not affect full participation in society.

If main requirements for the success of this model were not available, this would result in structural inequality, described by Fraser as maldistribution, misrecognition, and misrepresentation. Therefore, social justice is not achievable in the absence of any of the key aspects. The economic aspect ensures what Fraser termed economic restructuring, income transfer and labour reorganisation. The second aspect, cultural component, ensures revaluing of an epilepsy identity and building of sense of self (Fraser, 2000). The last component, the political, ensures the needs and claims of people with epilepsy are articulated. In between the aspects and requirements lay barriers to participation. Recalling that Fraser put parity of participation at the centre of economic, cultural and political justice, social justice would allow people with epilepsy to participate in society as peers (Fraser, 2004, 2008, 2011).

To achieve participation, the model recognises some aspects that should be streamlined such as gender, age geographical location, seizure type and research needs. Mainstreaming is required to ensure that children, the elderly services, rural dwellers, women and those with absence seizures are not left out of epilepsy programs.

Therefore, it is suggested that the results could be generalised to most African countries because the issues reported herein represent an Africa-wide challenge in managing epilepsy

(Birbeck, 2000; Duggan, 2013; Mushi et al., 2011; Nuhu et al., 2010; Watts, 1989). Literature showed that epilepsy stigma existed in indigenous, Muslim, and Christian African societies, and in urban and rural areas (Birbeck, 2000; Birbeck et al., 2006; Mushi et al., 2011; Watts, 1989). Like Zimbabwe, most African communities have limited public services offering health care, social welfare, and employment support (ILO, 2015, 2016; WHO, 2005, 2011, 2015, 2016). Although this study focused on epilepsy Zimbabwe, the findings may well have a strong bearing on epilepsy and disability in Africa. Therefore, the model suggested in the next section has been designed with the African situation in mind.

## *Implications for social work education and practice*

### *Education*

The findings have several implications for social work education and practice. Social work training curricula must enhance their focus on human rights and social justice. In countries in the Global South, social justice could be achieved through developmental social work practice that includes social action, empowerment, awareness-raising, and advocacy. As Fraser (2001) noted, curative or remedial social work does not necessarily allow people with disabilities to participate as peers. However, remedial social work is an appropriate medium to work with individuals and families to develop life plans in keeping with their education, training, and work aspirations; provide psychosocial support to nurture resilience; and enhance awareness of the social factors limiting employment opportunities. Rights-based approaches protect and nurture social, economic, cultural, and political rights. Pivotal for this research was the right to employment. Social workers must promote decent work, where people with epilepsy can earn a liveable wage, and social protection to support people (redistribution), and participation (representation and recognition) to give marginalised people a voice.

*Practice*

Professionals and organisations providing services, such as the ESF, advocate for the rights of people with epilepsy and use empowerment strategies to fight for their rights; they challenge injustice and, resources permitting, provide legal services to ensure that people with epilepsy have access to courts. Social workers need to work closely with these organisations and networks to ensure appropriate services are received, including professional associations or regulating bodies such as the National Association of Social Workers, Nurses Council of Zimbabwe, Zimbabwe Traditional Medicines Council, Zimbabwe Teachers Association, Zimbabwe Medical Association, Council of Social Workers, Allied Health Practitioners Council, and Institute of Personal Management of Zimbabwe, among others. They extend to training institutions, such as Zimbabwe Institute of Public Administration and Management (ZIPAM), colleges, universities, and vocational training centres. Professionals and service providers must be supported to be able to understand the needs of people with epilepsy to change negative social attitudes. They should take a developmental approach to help people with epilepsy develop entrepreneurial skills and income-generating projects. An integrated developmental approach, with justice at its core, works through collaborative partnerships between people with epilepsy and their families, employers, trainers, employees, service providers, and government officials.

Key goals and targets need to be put in place to ensure the implementation of effective strategies. Table 9.3 lists five goals and 17 targets to eradicate misconceptions and ongoing negative social attitudes about epilepsy and ensure: (i) medical treatment for all people with epilepsy, ensure adequate work skills and employment positions for people with epilepsy, (ii) adequate and inclusive policies for people with epilepsy, and (iii) adequate and inclusive services for people with epilepsy. One of the targets suggested in Table 9.3 is research into epilepsy and employment. Areas for research are suggested in the next section.

**Table 9.3: Social work with people with epilepsy**

| Goals | Targets |
|---|---|
| 1. **Eradicate misunderstanding and negative social attitudes about epilepsy** | 1. Public health education and awareness to combat negative social attitudes focusing on family, school, workplace and community.<br>2. Sensitisation of traditional healers and service providers. |
| 2. **Ensure medical treatment for all people with epilepsy** | 1. Access to medical treatment to ensure early control of seizures and streamlined epilepsy interventions to complement medical treatment. |
| 3. **Ensure adequate work skills and employment positions for people with disabilities** | 2. Basic education to enhance basic work skills.<br>3. Increase the number of people with disabilities in vocational training to acquire work skills appropriate for the Zimbabwe job market.<br>4. Job readiness programs and employment services.<br>5. Increase access to formal employment in the public and private sectors.<br>6. Supportive employment workplace policies to ensure fairness in the workplace.<br>7. Developmental approach that enhances opportunities within the informal sector. |
| 4. **Ensure adequate and inclusive policies for people with disability.** | 8. Disability inclusion policies for all private, public and voluntary institutions and employers.<br>9. Resource provision to create a positive supportive environment, including social assistance to facilitate employment access and retention.<br>10. Inclusion of people with disabilities in policy-making structures to enhance voice and representation.<br>11. Create legal channels for recourse to justice. |
| 5. **Ensure adequate and inclusive services for people with epilepsy.** | 12. Service provider capacity building to ensure quality service provision.<br>13. Improve basic education, welfare, and health services.<br>14. Foster research in epilepsy and employment.<br>15. Ensure adequate funding is available for services. |

## Suggestions for further research

The researcher five areas for future research. First, given the increasing emphasis on social development in African social policy, future research could focus on micro developmental practice for people with epilepsy and what could be the best ways to assist people with epilepsy in developing innovative income-generating enterprises. This is especially important in

Zimbabwe, where huge formal employment barriers remain to an extent that there is a need to explore alternative and informal employment that have the potential to provide a liveable wage to people with epilepsy. Secondly, research could focus on strategies of enhancing the biopsychosocial spiritual model as well as the cultural and religious practices that are used in managing epilepsy in Zimbabwe. This must be accompanied by a research program on the effectiveness of traditional treatments and a search for common ground between traditional and medical interventions. Thirdly, carers of some people with epilepsy provided a social and economic role that deserved to be understood better through research. Research is required to ascertain the nature and quality of support services for people with epilepsy and other forms of disability at community, primary, secondary, and tertiary educational centres. Fourthly, while stigma has been extensively explored by previous researchers, further research is suggested on stigma associated with modern epilepsy medicines and stigma associated with traditional epilepsy treatments. Fifthly, another key question for research could be strategies to optimise the representation of people with epilepsy in policy-making processes and to strengthen grassroots organisations of people with epilepsy. Finally, a focus on income, employment and livelihoods of people with epilepsy in rural areas is suggested.

## Conclusion

This chapter discussed findings, proffered conclusions, shared implications and made suggestions for future research. Recalling the story of Berna Mwenje that supported the rationale for this research in Chapter 1, Berna's experiences, as well as those of the 30 people with epilepsy in this research, is now clear. While their unemployment was viewed as an individual problem, it turned out to be a largely structural issue emanating from an unjust system that denied them opportunities to participate in employment as peers. Employment opportunities for people with epilepsy, as with those for most people with disabilities in

Zimbabwe, remain precarious due to avoidable structural barriers, such as negative beliefs and inaccessible public services. There is an urgent need for economic, cultural and political initiatives that address these barriers. It is hoped that the results of this research, the implications of the findings, and the Comprehensive Epilepsy-Management Model proposed will contribute, albeit in a small way, to the realisation of employment opportunities that meet the expectations of people with epilepsy in Zimbabwe. Although this study focused on epilepsy Zimbabwe, the findings may well have a strong bearing on epilepsy and disability in Africa. So, let people with disability participate as peers in 'cooking delicious meals' as participant Maziziba observed:

> Employers should not judge me because they don't know what I am capable of doing. If I applied to be a cook, I will prove them wrong by cooking a meal they will never forget, a delicious one.

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# Appendices

# Appendix 1 Preliminary report presented to service providers

**RESEARCH FOCUS:** DISABILITY, EMPLOYMENT AND SOCIAL JUSTICE

**PARTICIPANTS:** EMPLOYED AND UNEMPLOYED PEOPLE WITH EPILEPSY WHO ARE MEMBERS OF EPILEPSY SUPPORT FOUNDATION (ESF) IN HARARE, ZIMBABWE

## INTRODUCTORY STATEMENT

These preliminary insights and realisations are emanating from an ongoing research on disability, employment and social justice being done by Mr. Jacob Mugumbate for his Doctorate Degree in Social Work at the University of Newcastle, Australia. This report is shared with participants for their information and with professionals providing employment and related services to people with epilepsy in order for them to give their opinions on the findings in a focus group discussion (FGD). It is hoped the FGD will help them understand issues from the perspective of people with epilepsy and ultimately this will help shape services they provide.

## METHODS EMPLOYED IN THE STUDY

### Procedures

The research involved in-depth interviews with 13 employed and 15 unemployed people with epilepsy who were all members of the Epilepsy Support Foundation (ESF). The sample consists of 30 people, so two more interviews with employed members are still pending. The interviews were mostly done at the ESF and were audio recorded mostly in vernacular Shona language. A few of these interviews have already been translated and transcribed. They were listened to or read several times to generate preliminary insights that are presented in this report.

**Participants' profiles**

All interviewed participants were on treatment. They mostly had their first seizures during childhood. They described their seizures as controlled. Half were females. Almost half were employed. Most stayed with their families. Many were single. Employment included formal and self-employment. Participants included four teachers, two nurses, general hands, broker, professional welder, professional painter, journalist, four traders and others.

**THEMATIC STATEMENTS**

**Experiences of people with epilepsy**

1. *I did not expect to get a job and work productively with epilepsy, but I did.*

2. *This was never what I aspired. I expected to be much more than this. Even my parents expected much more.*

3. *Things only got better when my seizures got treated.*

4. *I did not finish my secondary education and professional training, my parents said they had no money for fees. My parents and community thought I could not do well at school, so they did not support me.*

5. *People think I am sick. They do not think that I can do the kind of jobs they do.*

6. *I would like to get a government job. It is more permanent and there is job security.* **In contrast:** *The private sector has opportunities, I lost a job at a government parastatal because of seizures.*

7. *I still feel my parents are overprotective. They don't believe in me. They still want to keep me at home.* **In contrast:** *My parents have very unrealistic expectations, always comparing me with my siblings and expecting me to achieve like them or any other person of my age.*

8. *When I lost that job because of epilepsy, I became withdrawn, I had no social life. I contemplated suicide a dozen times.*

9. *Even when you disclose, even when people smile at you, at times you can feel some negativity. Co-workers still think you are mentally ill, they mistrust you.*

**Facilitators and barriers to employment for people with epilepsy**

1. *There was no professional support available to me in relation to job seeking.*

2. *I feel I was empowered at the Foundation where I sought help. Without them, I don't think I would have moved on to acquire a job or training that I have today.*

3. *I think I am doing well because of my supportive family.*

4. *Employer trust should be gained through disclosure.* **In contrast:** *I never disclosed, I feared I would lose the job.*

5. *Seizures affect memory and learning, they determine the work I do. I think my memory is my biggest letdown.*

6. *A good education provides good opportunities.*

7. *I only got this job because I have a relative or someone I knew working there.*

8. *There are some working conditions not favourable for me. These trigger seizures. I need a more favourable working environment.*

**Strategies to improve employment**

1. *Reduce stigma in society. Let people know that people with epilepsy have capacities, that they are not mentally ill and that epilepsy and that they are normal human beings.*

2. *The government should ensure specific jobs are reserved for people with epilepsy*

3. *People with epilepsy should accept their condition. Acceptance of the condition by the person with epilepsy is a key issue.*

4. *They should be agents of change and should be role models of the good things they can do.*

5. *I think there is need to match capacity with type of job and type of training.*

6. *I think it is government's responsibility to help us get jobs. There must be a quota system and protected workshops*

7. *Disclose that you have epilepsy. If the workplace becomes familiar with your condition, you are unlikely to lose the job and likely to be accepted.*

8. *Deal with triggers like working under the sun, working long hours, sleep deprivation etc*

9. *Treatment adherence*

## DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

1. Even the successful stories are not known by society, they must be let known through publicity on wide media. Successful stories have very resilient participants, who often gave up in the middle, got successfully treated, accepted their condition, got work and now have developed high self-esteem.

2. Legal battles are not fought even when people are dismissed from work illegally. Organisations must provide legal advice.

3. Psychosocial issues are a huge burden when it comes to employment, these should be addressed through awareness and job training

4. There is need to capacitate professionals so that they play roles that promote economic independence of people with epilepsy.

5. Work aspirations are diverse. One participant's aspirations were centred on art as a means of getting income.

6. Women have a triple burden: workers/income earners, mothers/wives and person living with a condition. Need for programs specific to this user group.

7. There is no consensus on disclosure. Area for further investigation.

8. Though not necessarily part of this research, the research discovered some problems: use of medical treatment as a last resort yet successful stories come after medical treatment.

**CONCLUSION**

There appears to be a vicious a cycle of problems for people with epilepsy: having epilepsy, no education or job training, joblessness, stress, more seizures, more stigma, less job opportunities, more stress and more seizures. It is hard at this moment to recommend a model to break this cycle but it is hoped at the end of the study, a model will be available.

# Appendix 2: Organisational information statement

Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Organisational Information Statement**

Title: Disability, employment and social justice: A case study of facilitators and barriers to employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr. Amanda Howard (Co-Supervisor) and Mr. Jacob Mugumbate (Student)

**For the attention of the Director of the Epilepsy Support Foundation (ESF)**

You are requested to provide your support and authorisation for the above mentioned research project being conducted by Mr Jacob Mugumbate, a lecturer at Bindura University, for his Doctor of Philosophy Social Work degree at the University of Newcastle supervised by Professor Mel Gray & Dr Amanda Howard of the School of Humanities and Social Science. This project has been approved by the Human Research Ethics Committee of the University of Newcastle (Approval Number H-2015-0145) and will take place in your organisation at the Epilepsy Centre in Hatfield, Harare from July 2015 to December 2015.

**Why is the research being done?**

The purpose of the research is to explore facilitators and barriers to employment for people with epilepsy. Due to stigma and discrimination supported by cultural distortions, very few people with epilepsy may find their way into employment. Consequently, theirs may be a triple burden compounded by their struggle with epilepsy, stigma and finding employment. This research is being done to explore these and other structural systemic factors with an objective

of involving people with epilepsy in finding solutions to increasing opportunities of gaining or maintaining employment.

**Who can participate in the research?**

This research has two categories of participants. These are:

- People with epilepsy aged 18-64 years selected purposively from those who respond to the advertisement calling for expressions of interest to participate.

- Professionals working with people with epilepsy in Zimbabwe selected purposively from staff members of the ESF and the Zimbabwe League Against Epilepsy. Senior employees and volunteers will be excluded from the focus group discussion.

**What participants would be asked to do?**

If they agree to participate, participants will be asked to:

- Interview participants will undergo an interview session with Mr Jacob Mugumbate, a qualified Social Worker. The interview will be audio recorded using a portable voice recorder. If the researcher has any concerns regarding the participant's welfare and participating in the interview, the participant will be asked to consent to ESF providing information about them.

- Focus group participants will undergo a group discussion with Mr Jacob Mugumbate. The group discussion will be audio recorded using a portable voice recorder.

- No reimbursement or payments will be made to participants or to the ESF.

**What would your organisation be asked to provide?**

Your organisation would be asked to provide:

- A room suitable to accommodate 2 people for a confidential interview

- Provide information about participants following their consent, where necessary.

- Facilities able to accommodate a focus group discussion, where needed.

- Placement of an advertisement on your noticeboards

**What choice do you have?**

Participation in this research is entirely voluntary. Only those people who give their informed consent will be included in the project. Whether or not people decide to participate, they will not be disadvantaged in any way and their decision will not affect their relationship with Mr Mugumbate. If they do decide to participate, they may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies them.

**How much time will it take?**

The interview should take about 60 minutes for each participant and about 60 minutes for the focus group discussion.

**What are the risks and benefits of participating?**

The interviews and group discussions may touch on previous employment issues that may make participants feel uncomfortable in which case if this arises, a list of free counselling service providers will be provided. It is hoped that the research will improve knowledge base for practitioners working to improve employment outcomes for people with epilepsy and will positively impact on their feelings of competency in dealing with epilepsy and employment issues. Further, it is hoped their practice behaviours will be improved.

**How will privacy be protected?**

Any information collected by the researchers which might identify participants will be stored securely and only accessed by the researchers unless they consent otherwise, except as required by law. The interview notes and audio records will be anonymous and it will not be possible

to identify participants from their answers. Numerical codes/identifiers will be used to ensure that audio records and notes remain anonymous. Data in electronic form will be kept secure in a password protected computer file with external hard-drive backup. While in Zimbabwe, data in paper form will be kept secure in a lockable handbag in the researchers' room accessible by the researcher only. The researcher intends to outsource transcription of interviews and the person to provide this service is going to be bound by a confidentiality agreement. In transit to Australia, data in paper form together with the laptop and external hard disk that stores electronic data will be kept secure in a lockable hand bag which the researcher will carry with him onto the flight. In Australia, data in paper form will be kept secure in a lockable table in the researchers' office where no one will have access to except the researcher. Data will be retained for at least 5 years at the University of Newcastle. The electronic data will be destroyed by deleting all files from the computer and hard disk while data in paper form will be destroyed by shredding.

**How will the information collected be used?**

The data will be reported in a thesis to be submitted for Mr Jacob Mugumbate's degree while parts of it will be presented at epilepsy, social work or employment conferences and published in papers in scientific journals. Individual participants will not be identified in any reports or presentations arising from the project. Participants will be able to review the recording and transcripts to edit or erase their contribution after the interview. Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law. Information shared will include facilitators and barriers to employment and suggested strategies. Participants will be asked during the interview if they could require a summary of the results so the researcher could sent them a copy. A copy of the final report will be deposited in the libraries of the University of Newcastle and Epilepsy Support Foundation.

**What do you need to do?**

Please read this Information Statement and be sure you understand its contents before you clear the research. If there is anything you do not understand, or you have questions, contact the researcher. If you would like this research project to take place, please provide the research permit and complete the attached Consent Form and return it to the researcher.

**Further information**

If you would like further information please contact the researchers using contact details provided below:

Jacob Mugumbate, Phone: +263772818317 or +61470457789 Email:

mugumbatej@buse.ac.zw or jacob.mugumbate@uon.edu.auProfessor Mel Gray, Phone:

+6124921 6233 Email: mel.gray@newcastle.edu.au

Thank you for considering this request.

Signature:_____                Signature:_____

**Name:** Professor Mel Gray                             **Name:** Mr Jacob Mugumbate

**Position:** Principal Supervisor                     **Position:** Student

**Complaints about this research**

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2015-0145. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, Telephone +61249216333, email Human-Ethics@newcastle.edu.au.

# Appendix 3: Organisational consent form

Professor Mel Gray
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Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Consent Form for the Epilepsy Support Foundation**

Title: Disability, employment and social justice: A case study of facilitators and barriers to

employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr Amanda Howard (Co-

Supervisor) and Mr Jacob Mugumbate (Student)

The Epilepsy Support Foundation (ESF) agrees to participate in the above research project and it gives its consent freely.

The ESF understands that the project will be conducted as described in the Information Statement, a copy of which it has retained.

The ESF understands that it can withdraw from the project at any time and do not have to give any reason for withdrawing.

The ESF understands that participants will be able to review their recording and transcripts to edit or erase their contribution after the interview.

The ESF consent to (circle YES to those activities you agree to participate in, and circle NO to those activities which you do not agree to participate in):
- Providing a research clearance for this research project                Yes/No
- Making advertisement for expressions of interest accessible to members  Yes/No
- Providing a room for interviews, where needed                          Yes/No
- Provide information about interview participants, where necessary        Yes/No
- Providing facilities for a focus group discussion, where needed         Yes/No
- Clearing its members of staff and volunteers for focus group discussion  Yes/No

The ESF understands that organisational and personal information will remain confidential to the researchers. The ESF has had the opportunity to have questions answered to my satisfaction.

**Print Name:** _____**Position**_____
**Contact phone number (for further contact about the study):**_____
**Signature:** _____**Date:** _____

# Appendix 4: Information statement for interview participants

Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Information Statement for Interview Participants**

Title: Disability, employment and social justice: A case study of facilitators and barriers to employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr. Amanda Howard (Co-Supervisor) and Mr. Jacob Mugumbate (Student)

You are invited to participate in the research project for the above mentioned research project being conducted by Mr Jacob Mugumbate, a lecturer at Bindura University, for his Doctor of Philosophy Social Work degree at the University of Newcastle supervised by Professor Mel Gray & Dr Amanda Howard of the School of Humanities and Social Science. This project has been approved by the Human Research Ethics Committee of the University of Newcastle (Approval Number H-2015-0145) and will take place in your organisation at the Epilepsy Centre in Hatfield, Harare from July 2015 to December 2015.

**Why is the research being done?**

This research is being done to understand factors shaping employment opportunities for people with epilepsy. This is important because very few people with epilepsy find their way into employment; making their situation very difficult. By involving some people with epilepsy in in this project, it is hoped this will help in finding solutions to increasing their employment opportunities.

**Who can participate in the research?**

This research has two categories of participants. These are:

- People with epilepsy aged 18-64 years selected purposively from those who respond to the advertisement calling for expressions of interest to participate.

- Professionals working with people with epilepsy in Zimbabwe selected purposively from staff members, volunteers and members of the ESF and the Zimbabwe League Against Epilepsy.

You were selected to consider this invitation to participate in this research as one of the people with epilepsy of working age.

**What participants would be asked to do?**

If you agree to participate, you will be asked to undergo an interview session with Mr Jacob Mugumbate, a qualified Social Worker and respond to follow up interview, if necessary. If the researcher has any concerns regarding your welfare and participating in the interview, you will also be asked to consent to the ESF providing information about yourself. No reimbursement or payments will be made to participants or to the ESF. The interview will be done at the ESF and where necessary at a place convenient to the participant and will be recorded verbatim using a portable voice recorder.

**What choice do you have?**

Participation in this research is entirely your choice. You will only be included in the project if you give informed consent. Whether or not you decide to participate, you will not be disadvantaged in any way and your decision will not affect your relationship with Mr Mugumbate. If you decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

**How much time will it take?**

The interview will take about 60 minutes for each participant.

**What are the risks and benefits of participating?**

The benefit of participating in this research is that you will contribute to knowledge on improving employment services for people with epilepsy and by sharing your own experience you are offering yourself an opportunity to be heard. The risk associated with the research is that the interview may touch on your previous unpleasant employment issues. If this happens, the researcher will look at the list of counselling service providers and choose an organisation to refer you to for counselling services.

**How will your privacy be protected?**

Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers unless they consent otherwise, except as required by law. The interview notes and audio records will be anonymous and it will not be possible to identify you from these records.  False names/identifiers will be used to ensure that audio records and notes remain anonymous.  Data in electronic form will be kept secure in a password protected computer file with external hard-drive backup. While in Zimbabwe, data in paper form will be kept secure in a lockable handbag in the researchers' room accessible by the researcher only. The researcher intends to outsource transcription of interviews and the person to provide this service is going to be bound by a confidentiality agreement. In transit to Australia, data in paper form together with the laptop and external hard disk that stores electronic data will be kept secure in a lockable hand bag which the researcher will carry with him onto the flight.  In Australia, data in paper form will be kept secure in a lockable table in the researchers' office where no one will have access to except the researcher. Data will be retained for at least 5 years at the University of Newcastle. The electronic data will be destroyed by deleting all files from the computer and hard disk while data in paper form will be destroyed by shredding.

**How will the information collected be used?**

A summary of findings from the interviews with participants with epilepsy will be provided to the group of professionals to form the basis for the focus group discussion. Further, the data

will be reported in a thesis to be submitted for Mr. Jacob Mugumbate's degree while parts of it will be presented at epilepsy, social work or employment conferences and published in papers in scientific journals. Individual participants will not be identified in any reports or presentations arising from the project. You will be able to review the recording and transcripts to edit or erase your contribution after the interview. Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law. Information shared will include facilitators and barriers to employment and suggested strategies. You will be asked during the interview if you require a summary of the results so the researcher could sent you a copy. A copy of the final report will be deposited in the libraries of the University of Newcastle and Epilepsy Support Foundation.

**What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher. If you agree to participate, please complete and sign the attached Consent Form and return it to the researcher who will contact you to arrange a time convenient to you for the interview.

**Further information**

If you would like further information please contact the researchers using contact details provided below:

Jacob Mugumbate, Phone: +263772818317 or +61470457789 Email:

mugumbatej@buse.ac.zw or jacob.mugumbate@uon.edu.auProfessor Mel Gray, Phone:

+61249216233 Email: mel.gray@newcastle.edu.au

Thank you for considering this invitation.

**Signature:**_____        **Signature:**_____

**Name:** Professor Mel Gray                        **Name:** Mr Jacob Mugumbate

**Position:** Principal Supervisor              **Position:** Student


**Complaints about this research**

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2015-0145. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, Telephone +61249216333, email Human-Ethics@newcastle.edu.au.

# Appendix 5: Information statement for interview participants

Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Consent Form for Interview Participants**

Title: Disability, employment and social justice: A case study of facilitators and barriers to

employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr. Amanda Howard (Co-

Supervisor) and Mr. Jacob Mugumbate (Student)

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing. You will be able to review the recording and transcripts to edit or erase your contribution after the interview.

I consent to:

(Circle YES to those activities you agree to participate in, and circle NO to those activities which you do not agree to participate in statement 1 and respond in the same manner to statement 2 if applicable):

1. Participating in an interview and having the interview audio recorded    Yes/No
2. Participating in a follow up interview, where necessary and
   having it audio recorded                                                 Yes/No
3. The ESF providing information about myself to the researcher, where
   there is concern regarding my welfare and participating in the interview. Yes/No

I understand that my personal information will remain confidential to the researchers.
I have had the opportunity to have questions answered to my satisfaction.

**Print Name:**        _____
**Contact phone number (for further contact about the study):**_____

**Signature:** _____**Date:** _____

Return completed form in the sealed envelope provided to: ESF, Attention Mr. Jacob Mugumbate

# Appendix 6: Interview guide for people with epilepsy

Document Version 2 expanded; Dated 18/10/15

# Disability, employment and social justice

A case study of facilitators and barriers to employment for people with epilepsy

in Harare, Zimbabwe

## INTERVIEW GUIDE FOR PEOPLE WITH EPILEPSY

### INTERVIEW INFORMATION

Interview participant ID_____Gender_____Employment status_____Identifier   [          ]

Place of Interview_____Time of Interview_____ Preferred language_____

Audio recording ID_____Length _____Date_____

### INTERVIEW STATEMENT

Thank you for agreeing to take part in this research and for coming for this interview. As indicated in the information statement, I am carrying out research to understand the factors affecting people with epilepsy from gaining or maintaining employment. This will be achieved through interviews with people like yourself and a focus group discussion with professionals working with you in providing employment services. This interview will be audio recorded so that I get a correct record of your responses. The audio record will be converted to a written document which I will bring to you for verification. Your name remains anonymous and it will not be possible to identify you with any data I will collect. All researchers and those who will provide transcription services will be bound by confidentiality. In this interview, I will informally discuss with you issues about your lived experiences, factors related to your employment, barriers and facilitators and strategies to improve employment services and outcomes, a guide of which has been provided. Throughout the interview, feel free to ask any question or to cancel the interview. You may ask questions about what I have said, if you have any now?

# Appendix 7: Research questions, prompts, and probes in English and Shona

| Research question *Mubvunzo wetsvakurudzo* | Prompts *Mubvunzo wekutanganyaya* | Probes *Mibvunzo midoko* |
|---|---|---|
| | Tell me about yourself? *Ndiudze nezveupenyu hwako* | Age, Marital status, Epilepsy, Qualifications *Makore, Kuroora/rwa, Pfari, Dzidzo* |
| What has been the experience of employed and unemployed people with epilepsy? *Ndezvipi zvawakasangana nazvo pawaiva pabasa kana pawanga usiri?* | Tell me about your employment experiences *Ndiudze zvawakasangana nazvo pawaishanda* | Sources of income. Where did you work? When? How long? *Unorarama sei? Wakashanda kupi nekupi? Riini? Kwenguva yakareba sei?* |
| | Tell me about your unemployment experiences *Ndiudze zvawakasangana nazvo pawaisashanda* | Why you became unemployed? Opportunities. Interviews. Aspirations *Sei waishaya basa? Mikana. Zvishiviro* |
| What are the structural systemic factors preventing people with epilepsy from gaining or maintaining employment? *Ndezvipi zvaikanganisa kuwana kana kuchengetedza basa?* | Tell me about the things that acted as barriers to your employment *Ndezvipi zvaikukanganisa panezvemabasa* | Role of Family, Employers, Policies, Epilepsy *Mhuri, vaShandirwi, Mitemo. Zvepfari* |
| | Tell me about the things that acted as facilitators to your employment *Ndeipi zvaiita kuti zvireruke panezvemabasa* | As above/*sepamusoro* |
| What are effective strategies for supporting employment for people with epilepsy? *Ndezvipi zvaunokurudzira zvingaita kuti kushanda kwevane pfari kuvandudzwe?* | Tell me about the strategies you think are useful to improve employment of people with epilepsy. *Ndiudze zvaunokurudzira* | Recommend to/*Kurudziro ku* -Government/*Hurumende* -People with epilepsy/*vane pfari* -Professionals/*Vabetseri* -Community and family/*Nharaunda nemhuri* -Welfare organisations/*masangano anobetsera* -Any other/*vamwewo* |

# Appendix 8: Information statement for service providers

Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Information Statement for Service Providers**

Title: Disability, employment and social justice: A case study of facilitators and barriers to employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr. Amanda Howard (Co-Supervisor) and Mr. Jacob Mugumbate (Student)

You are invited to participate in the research project for the above mentioned research project being conducted by Mr Jacob Mugumbate, a lecturer at Bindura University, for his Doctor of Philosophy Social Work degree at the University of Newcastle supervised by Professor Mel Gray & Dr Amanda Howard of the School of Humanities and Social Science. This project has been approved by the Human Research Ethics Committee of the University of Newcastle (Approval Number H-2015-0145) and will take place in your organisation at the Epilepsy Centre in Hatfield, Harare from July 2015 to December 2015. Participants will be required to respect the confidentiality of the group discussions.

**Why is the research being done?**

The purpose of the research is to explore facilitators and barriers to employment for people with epilepsy. Due to stigma and discrimination supported by cultural distortions, very few people with epilepsy may find their way into employment. Consequently, theirs may become a triple burden compounded by their struggle with epilepsy, stigma and finding employment. This research is being done to explore these and other structural systemic factors with an

292

objective of involving people with epilepsy in finding solutions to increasing opportunities of gaining or maintaining employment.

**Who can participate in the research?**

This research has two categories of participants. These are:

- People with epilepsy aged 18-64 years selected purposively from those who respond to the advertisement calling for expressions of interest to participate.

- Professionals working with people with epilepsy in Zimbabwe selected purposively from staff members of the ESF and the Zimbabwe League Against Epilepsy. Senior employees and volunteers will be excluded.

You were selected to consider this invitation to participate in this research as one of the professionals.

**What participants would be asked to do?**

If you agree to participate, you will be asked to participate in a focus group discussion with colleagues from the ESF facilitated by Mr Jacob Mugumbate, a qualified Social Worker and respond to a follow up interview, if any. The discussion will be held at the ESF. A voice portable voice recorder will be used to record the discussion. Participants will be required to respect the confidentiality of the group discussions. No reimbursement or payments will be made to participants or to the ESF.

**What choice do you have?**

Participation in this research is entirely your choice. You will only be included in the project if you give informed consent. Whether or not you decide to participate, you will not be disadvantaged in any way and your decision will not affect your relationship with Mr Mugumbate. If you decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

**How much time will it take?**

The focus group discussion should take about 60 minutes.

**What are the risks and benefits of participating?**

The benefit of participating in this research is that you will contribute to knowledge on improving employment services for people with epilepsy. There are no risks associated with this research for you.

**How will your privacy be protected?**

Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers unless they consent otherwise, except as required by law. Participants will be required to respect the confidentiality of the group discussions and this requirement will be reminded to participants in the introductory statement before the start of the group discussion. The interview notes and audio records will be anonymous and it will not be possible to identify you from their answers. Numerical codes/identifiers will be used to ensure that audio records and notes remain anonymous. Data in electronic form will be kept secure in a password protected computer file with external hard-drive backup. While in Zimbabwe, data in paper form will be kept secure in a lockable handbag in the researchers' room accessible by the researcher only. The researcher intends to outsource transcription of interviews and the person to provide this service is going to be bound by a confidentiality agreement. In transit to Australia, data in paper form together with the laptop and external hard disk that stores electronic data will be kept secure in a lockable hand bag which the researcher will carry with him onto the flight. In Australia, data in paper form will be kept secure in a lockable table in the researchers' office where no one will have access to except the researcher. Data will be retained for at least 5 years at the University of Newcastle. The electronic data will be destroyed by deleting all files from the computer and hard disk while data in paper form will be destroyed by shredding.

**How will the information collected be used?**

The data will be reported in a thesis to be submitted for Mr. Jacob Mugumbate's degree while parts of it will be presented at epilepsy, social work or employment conferences and published in papers in scientific journals. Individual participants will not be identified in any reports or presentations arising from the project. You will be able to review the recording and transcripts to edit or erase your contribution after the discussion. Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law. You will be asked during the interview if you require a summary of the results so the researcher could sent you a copy. A copy of the final report will be deposited in the libraries of the University of Newcastle and Epilepsy Support Foundation.

**What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher. If you agree to participate, please complete and sign the attached Consent Form and return it to the researcher who will contact you to arrange a time convenient to you for the interview.

**Further information**

If you would like further information please contact the researchers using contact details provided below:

Jacob Mugumbate, Phone: +263772818317 or +61470457789 Email:

mugumbatej@buse.ac.zw or jacob.mugumbate@uon.edu.auProfessor Mel Gray, Phone:

+61249216233 Email: mel.gray@newcastle.edu.au

Thank you for considering this invitation.

**Signature:**_____         **Signature:**_____

**Name:** Professor Mel Gray                    **Name:** Mr Jacob Mugumbate

**Position:** Principal Supervisor                    **Position:** Student

**Complaints about this research**

This project has been approved by the University's Human Research Ethics Committee, Approval Number H-2015-0145. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, Telephone +61249216333, email Human-Ethics@newcastle.edu.au.

# Appendix 9: Consent for service providers



Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts University Drive
Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

**Consent Form for Service Providers**

Title: Disability, employment and social justice: A case study of facilitators and barriers to employment for people with epilepsy in Harare, Zimbabwe

Researchers: Professor Mel Gray (Principal Supervisor), Dr Amanda Howard (Co-Supervisor) and Mr Jacob Mugumbate (Student)

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing. I will be able to review the recording and transcripts to edit or erase my contribution after the discussion.

I consent to:

(Circle YES to those activities you agree to participate in, and circle NO to those activities which you do not agree to participate in statement 1 and respond in the same manner to statement 2 if applicable):

1. Participating in an interview and having the interview audio recorded    Yes/No
2. Participating in a follow up interview, where necessary and
   having it audio recorded                                                 Yes/No

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

**Print Name:**        _____
**Contact phone number (for further contact about the study):**_____
**Signature:**        _____**Date:** _____

Return completed form in the sealed envelope provided to: ESF, Attention Mr. Jacob Mugumbate

# Appendix 10: Focus group discussion guide

**Disability, employment and social justice:**

A case study of facilitators and barriers to employment for people with epilepsy in Harare, Zimbabwe

**FOCUS GROUP DISCUSSION GUIDE FOR SERVICE PROVIDERS**

## GUIDE DETAILS

Date_____Number of participants_____

Venue_____ Time: From _____To_____

Audio recording ID_____Length_____

## INTRODUCTORY STATEMENT

Thank you all for agreeing to take part in this research and for coming to this focus group discussion. As indicated in the information statement, I am carrying out research to understand factors affecting people with epilepsy from gaining and maintaining employment. This will be achieved through interviews with employed and unemployed people with epilepsy and a focus group discussion with professionals here now. The discussion will be audio recorded so that I get a correct record of all responses. The audio record will be converted to a written document which I will bring to you for verification. Your names remain anonymous and it will not be possible to identify you with any data collected in this discussion. In this discussion, I will informally discuss with you issues about your services to people with epilepsy, and your perspectives on structural systemic factors related to their responses to questions on lived experiences, employment barriers and facilitators, and strategies to improve employment services and outcomes. The discussion will be based on preliminary findings from my interviews with people with epilepsy, a copy of which I have already given to you. Throughout the interview, feel free to ask any question or to cancel your participation. I remind you that all participants should keep information from this discussion confidential. Do you have any questions?

## GUIDING QUESTIONS

1. Services to people with epilepsy

    a. What employment services do you provide to people with epilepsy?

    b. What do you hope to achieve by those services?

2. Lived experiences of people with epilepsy

    a. People with epilepsy's lived experiences in relation to employment can be summarized as follows: (Interviewer reads them out)

    b. What are your views on these perspectives?

3. Structural systemic factors
    a. People with epilepsy pointed out the following as the structural systematic factors affecting them from gaining or maintaining employment (Interviewer reads them out)
    b. What are your views on these structural systemic factors affecting people with epilepsy?
4. Strategies to improve employment services
    a. People with epilepsy recommended the following to improve employment services. (Interviewer reads them out)
    b. What are your views on these recommendations?
5. Do you have any other issues?

Thank you for participating in this discussion.

# Appendix 11: Participant recruitment flier

Professor Mel Gray
School of Humanities and Social Science
Faculty of Education and Arts
University Drive Callaghan NSW 2308 Australia
Phone: +61 2 4921 6233 Fax: +61 2 4921 7818
Email: mel.gray@newcastle.edu.au

Call for expressions of interest to participate in research on
**EMPLOYMENT FOR PEOPLE WITH EPILEPSY AT THE EPILEPSY SUPPORT FOUNDATION (ESF) IN HARARE**

**Who can participate?**
- People with epilepsy
- Members of the ESF
- Female or male
- Between 18 and 64 years
- Employed or unemployed

**What would you be asked to do?**
If you agree to participate, you will be asked to undergo an interview session at the ESF with Mr Jacob Mugumbate, a qualified Social Worker and respond to follow up interview, if necessary.

**Interested?**
For further information and to find out if this study is for you please contact Mr Jacob Mugumbate on +263772818317 or +61470457789 or email: mugumbatej@buse.ac.zw or jacob.mugumbate@uon.edu.au

**Project supervisors**
Professor Mel Gray, Phone: (+61) 2 4921 7322 Email: mel.gray@newcastle.edu.au and Dr. Amanda Howard Phone: (+61) 2 4921 7322 Email: amanda.howard@newcastle.edu.au

**RESEARCH STUDY**

www.newcastle.edu.au

**Complaints about this research**
*This project has been approved by the University's Human Research Ethics Committee, Approval Number H-2015-0145. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan*

*NSW 2308, Australia, Telephone +61249216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).*

# Appendix 12: Organisation support letter

**43 ST DAVID ROAD HATFIELD**
**HARARE ZIMBABWE**
**TELEPHONE: +263-4-571225**
**FAX: +263-4-4-571233**
**CELLPHONE: +263-4-773595241**
EMAIL: epilepsyzimbabwe@gmail.com
www.facebook.com/epilepsy.zimbabwe

To
Jacob Mugumbate
School of Social Sciences and Humanities
University of Newcastle, Newcastle, NSW
Australia

3 November 2014

Reference: **Letter of Support**

We acknowledge receipt of your request for research support for your research project on disability, employment and social justice.

The Foundation is happy to work with you throughout the research project and we are therefore able to provide the necessary support. We request that you make available to our library the final report, and any other publications accruing from this research project.

Feel free to get in touch with me if you need any further help.

Yours sincerely

R. Gwatinyanya
Acting Director