

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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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

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

<i>Uroyi</i>	Witchcraft
<i>Vadzimu</i>	Ancestors
<i>Zvikwambo</i>	Goblins (singular <i>Chikwambo</i> , also known as <i>zvidhoma</i> , <i>tokoroshi</i> , or <i>zvishiri</i>)

Words from other countries

<i>Jinn</i>	Evil spirits or demons in Arab language
<i>Fquih</i>	Islamic religious scholar
<i>Jadu/dua</i>	Witches in Afghanistan
<i>Jadugar</i>	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.