

A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services Available among Zambian Families of Children with Autism Spectrum Disorders.

By

Joachim Nyoni

Student Number: NYNJOA002

A thesis presented for the **Degree of Doctor** of Philosophy in Disability Studies in the
Department of Health and Rehabilitation Sciences

Supervisor: Professor Judith McKenzie

Co-Supervisor: Dr Michal Harty



University of Cape Town

December 2021

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

DECLARATION

I, **Joachim Nyoni**, hereby declare that this thesis titled, A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services Available among Zambian Families of Children with Autism Spectrum Disorders is my work (except where acknowledgements indicate otherwise), and it has not been submitted to any other University for a degree or examination. I also do hereby declare that all the sources of information I have used or quoted have been acknowledged and indicated through completed references. I have used the 6th American Psychology Association referencing style.

Signed:

Signed by candidate

Name: **JOACHIM NYONI**

ACKNOWLEDGEMENTS

This research study involved a lot of people, but without their support I would not have achieved my goal. To my three children, Katisha Siabonga Nyoni, Sizwayo Nyoni and Mphatso Nyoni, you believed in me and stood by me. To my wife, Fani Banda Nyoni, you have been a pillar in my academic world, from a Certificate to a Diploma, Masters and, finally, a Ph.D, you supported me and were always taking care of our children when I was away. You continued encouraging me when I felt like giving up.

To my young brother, Dr Emmanuel Lungu, and his wife, Ing'utu Mufana Lungu, thank you for your financial and emotional support. I would like to thank my mother, Godfridah Patrino Lungu, for educating the three siblings as a single mother. She planted in us the fear of God, love for all humanity, and always excelling in whatever we do.

May I also thank all administrators in ASD assessment Centres and Special Schools and Special Units in the Lusaka province of Zambia for their support in identifying ASD parents and professionals and for also taking part in the study.

To all Zambian parents of children with ASD and professionals who took part in this study, I thank you all for your contribution in making this research a reality. Your experiences and resilience with the current ASD support services in Zambia are so rich that you are counted amongst the strongest parents on earth. I will always be indebted to you all.

I would further like to thank my supervisors, Professor Judith Anne McKenzie and Co-Supervisor Dr. Michal Harty, for the support they rendered to me, starting from the project proposal which had to change several times, to ethics clearance, data collection, final report writing and graduation. I would like to thank you for your advice, critical guidance, comments and encouraging me to soldier on with this work. You made Cape Town become a city away from home. The spirit of Ubuntu is in you and your family. I will always be indebted to Professor Judith McKenzie and Dr Michal Harty for the rest of my life.

I am also grateful to my mentors and consultants, Professors Petrus Devries, Professor Roy McConkey, Dr. Deryck Sherriffs, Prof Theresa Lorenzo from the University of Cape Town, and Dr Tamara Chansa-Kabali from the University of Zambia for her academic support both as a parent of a child with ASD and as a participant. I would also like to thank Professor

Robert Serpell from the University of Zambia. Others are Dr Eden Padayachee from the Neuro Leadership Institute and Dr Patrick Mapulanga, Kamuzu University, Health Sciences, for critiquing the work.

Thank you to all Ph.D. students in disability studies, mostly Kofi Nseibo (Ghana) and Moses Amani Karisa (Kenya), for support and being brothers during trying moments, most of all when I lost my father, sister and three cousins within a year. We are a big family. One Africa.

Lastly, to all my workmates at the Ministry of Education Headquarters, Lusaka, Zambia. Mostly those in the Directorate of Early Childhood Education for their support.

SCHOLARSHIP FUNDING

I would like to thank and acknowledge the following funders:

- *Canon Collins:* Cannon Collins, the major funders of my study under the Morgan Family of the United Kingdom. I will remain a Cannon Collins Scholar and a social justice advocate for the rest of my life.
- *International Society for the Study of Behavioural Development (ISSBD):* Thanks for the award of a Developing Country Scholarship. I would like to thank the chairperson, Professor Peter Smith, and his team for the confidence they had in awarding me the scholarship.
- *University of Cape Town scholarship:* For the award of the international student scholarship, conference travel grants and Faculty of Health training grants.

DEDICATION

- This work is dedicated to our 18 years old second-born son, **Sizwayo Nyoni**, who was diagnosed with **autism in 2005** at the age of five years.
- It is also dedicated to Dr. Kenneth David Kaunda who died on 17th June 2021 (1924-2021). Kenneth Kaunda was the founding father of Zambia and the first republican president of Zambia who united Zambia under the social inclusion philosophy of One Zambia One Nation. He united and fought for political and independence freedom in Southern African region using his Biblical teaching of ‘Love your neighbours as you love yourself’.

TABLE OF CONTENTS

DECLARATION	i
ACKNOWLEDGEMENTS	ii
SCHOLARSHIP FUNDING.....	iv
DEDICATION.....	v
OPERATIONAL DEFINITIONS.....	xv
LIST OF TABLES	xviii
LIST OF FIGURES.....	xix
ABSTRACT	xx
PREAMBLE: A JOURNEY WITH EXPERIENCE	xxiii
CHAPTER ONE:.....	1
INTRODUCTION	1
1.0 Background of the Thesis: Setting the Scene.....	1
1.1 Overview	1
1.2 Context of the study.....	3
1.3 PAR approach among Zambian parents of children with ASD	6
1.4 The theoretical frameworks guiding the study	7
1.5 Significance of the study: Research and theory	8
1.6 Significance of the study: Research and practice	8
1.7 Research problem	8
1.8 Research aim	10
1.9 Main questions	10
CHAPTER TWO:	17
THEORETICAL FRAMEWORKS.....	17
2.0 Overview	17
2.1 Medical Models.....	17
2.2 Social model.....	19
2.3 Disability studies in family support services, social justice, and Human rights	21
2.4 Towards the selection of theoretical frameworks.....	25
2.5 Critical-emancipatory Theory (CET): A Historical Emancipatory Perspective	25
2.6 Emancipatory Disability Research (EDR)	28
2.7 Linking Emancipatory Disability Research (EDR) to PAR.....	28
2.8 Linking PAR to Critical-emancipatory theory	29

2.9 The Bronfenbrenner Bio-Ecological Systems Theory (BEST).....	30
2.10 The Bio-ecological Systems Theory (BEST) and Research	33
2.11 The link between the theoretical frameworks and the PAR approach.....	33
2.12 Summary of the Chapter	34
CHAPTER THREE:	36
LITERATURE REVIEW.....	36
3.0 Overview	36
3.1 Understanding ASD as a neuro-developmental disorder.....	37
3.2 What is autism spectrum disorder (ASD)?	37
3.3 The global prevalence rates of ASD.....	38
3.4 The evolution of ASD diagnosis and treatment	39
3.5. Parents’ experiences with formal and informal ASD support services	40
3.5.1 Parents’ experiences with formal and informal support services	40
3.5.2 Burdens of caring and raising a child with ASD: International perspective.....	44
3.5.3. Parents’ experience with ASD in Southern African region	45
3.5.4 The burden of caring and raising a child with ASD among Zambian families.....	46
3.5.5 ASD understanding and awareness in Zambia.....	48
3.5.6 Public knowledge about ASD in Zambia.....	48
3.5.7 Stigma and discrimination towards parents and children with ASD	49
3.5.8. Understanding disability policies in Zambia.....	50
3.6 Professionals ‘experiences in providing formal support services to families of children with ASD.....	53
3.6.1 Medical Professionals ‘experiences in providing formal support services to families of children with ASD	53
3.6.2 African traditional healers’ experiences in providing formal support services to families of children with ASD	55
3.6.3 Religious leaders’ experiences in providing formal support services to families of children with ASD.....	57
3.7 Application of PAR in Parents Empowerment.	60
3.8 Summary of the chapter	62
CHAPTER FOUR.....	63
RESEARCH DESIGN AND METHODS	63
4.0 Overview	63
4.1 Section 1: Methodology	65

4.1.1 Selection between qualitative and quantitative methodologies.....	65
4.1.2 Adopting qualitative research for this study	65
4.2 The choice of PAR to achieve emancipatory disability research aims.....	66
4.3 Participatory Rural Appraisal (PRA).....	67
4.4 Confirming PAR as an appropriate methodology	69
4.5 Potential pitfalls of PAR	70
4.6 Section 2: Methods and study Design	71
4.7 The field teams	71
4.8 Entering the community.....	72
4.9 Research plan	73
4.10 Aims of the study.....	73
4.11 The objectives of the study as informed by PAR.....	73
4.12 Defining action cycles	73
4.13 The thesis design timeline	75
4.14 Sampling sites and informants	75
4.15 The study setting.....	76
4.16 Recruitment of parents.....	78
4.16.1 Inclusion criteria for parents.....	79
4.16.2 Exclusion criteria for parents	80
4.17 Recruitment of professionals.....	81
4.17.1 Inclusion criteria for professionals	82
4.17.2 Exclusion criteria for professionals	82
4.18 Obtaining ethics clearance and informed consents	83
4.19 Informed consent	84
4.19.1 Informed consent from parents.....	84
4.19.2 Informed consent from professionals	85
4.20 Data collection tools	85
4.3: Data collection tools.....	85
4.20.1 How data was collected in Phase one	86
4.20.2 Focus group interviews (Parents only)	87
4.20.3 In-depth semi-structured interviews (professionals only).....	90
4.20.4 Observation	90
4.20.5 Daily field notes.....	91

4.20.6 Reflective learning and action learning	91
4.21 Phase two	91
4.21.1 Selection of participants.....	91
4.21.2 Data collection tools	92
4.21.3 Workshop	92
4.21.4 Plenary sessions.....	93
4.21.5 Other instruments used to collect data in Phase two	93
4.22 Audio, video, and photos	94
4.23 Data analysis	94
4.23.1 Step one: Compiling data	95
4.23.2 Step two: Disassembling data.....	96
4.23.3 Step three: Reassembling the data	96
4.23.4 Step four: Interpretation of the meaning of the data.....	97
4.23.5 Step five: Conclusion.....	97
4.24 Verification of the authenticity of the data	97
4.24.1 Credibility.....	97
4.24.2 Transferability	98
4.24.3 Dependability	98
4.24.4 Confirmability	99
4.24.5 Data management	99
4.24.6 Description of risks and benefits	99
4.24.7 Privacy and confidentiality.....	100
4.25 Sensitivity to potential bias	100
4.26 Summary of the chapter	100
CHAPTER FIVE	102
IDENTIFYING THE STATE OF THE PROBLEM: THE FINDINGS- PART ONE.....	102
5.0 Overview	103
5.1 Theme 1: Juggling multiple sources of ASD knowledge	106
5.1.1 Sub-theme 1: Western perspective: Knowledge about autism as defined in diagnostic manuals.....	107
5.1.2 Meaning vs definition of ASD	107
5.1.3 Behaviours associated with ASD as a condition	108
5.2 Sub-theme 2: Role of the religion in causal explanations of autism	112

5.2.1 Parents' negative experience with religion	112
5.2.2 Discriminatory views that religious leaders have toward children with ASD (from the parents' perspective)	115
5.3 Sub-theme 3: ASD causal explanations from traditional perspective	116
5.3.1 Culturally rooted beliefs about the causes of disabilities.....	116
5.3.2 Community sympathy	120
5.4 Theme 2: Community and informal support services	121
5.4.1 Sub-theme 1: fear, anxiety, and stress	121
5.4.2 Uncertainty of the future.....	122
5.4.3 The urgent need for counselling services.....	122
5.4.4 ASD children are God's special gift	123
5.5 Sub-theme 2: Stigma and abuse	124
5.5.1 Mistreatment and discrimination	124
5.5.2 Ill-informed community members.....	126
5.6 Sub-theme 3: Inadequate parent-led support groups	130
5.6.1 Limited parent support groups	130
5.6.2. Urgency for collaboration	131
5.7 Theme 3: ASD specific knowledge and formal services	132
5.8 Sub-theme 1: Developing skills to manage ASD	132
5.8.1 Capacity building.....	133
5.8.2 Self-reliance	134
5.9 Sub-theme 2: Shortage of personnel and resources.....	135
5.9.1 The desire for specialised services	135
5.9.2 Costly services.....	138
5.9.3 Non-standardised diagnostic tools.....	140
5.10 Sub-theme 3: Inadequate ASD policy development and implementation	141
5.10.1 The desire for specific ASD policy frameworks	141
5.10.2 The urgency for affirmative action on existing policies	143
5.11 Summary of the chapter	144
CHAPTER 6: PARTNERSHIP IN ACTION: RESEARCH FINDINGS ON A PARENT-LED SUPPORT GROUP	145
6.0 Overview	145
6.1 Recruitment of parents.....	145

6.3 Section One: Action learning and reflective meetings in both rural and urban settings	148
6.5. Action Cycle 1: Formation of a parent-led support group.....	155
6.5.1 Plans: The significance of forming a parent-led support group	155
6.5.2 Action: Electing the leadership	158
6.5.3 Observation: We need to target the local community	159
6.6 Action Cycle 2: Taking ASD awareness to higher institutions of learning	160
6.6.1 Plans: We can go to higher learning institutions	161
6.6.2 Action: Being a parent of a child with an “invisible disability” is a lonely journey	161
6.6.2.1 Strategy one: Parent narrative-centred approach.....	162
6.6.2.2 Strategy two: Practical demonstrations	163
6.6.2.3 Strategy three: Facilitating a question-and-answer session	164
6.6.3 Observations	166
6.6.4 Reflection and learning: Professionals as novices of ASD	167
6.6.4.1. Lessons learned: Low knowledge and understanding of ASD among members of staff in higher institutions of learning	167
6.6.4.2. Benefits of using variation in dialogue techniques	168
6.6.4.3 Time management and resiliency	168
6.7 Action Cycle 3: Parent-professional partnership.....	169
6.7.1 Plans: Participatory workshop	169
6.7.2 Action: Enlisting for support	169
6.7.2.1 Topic 1: Understanding the developmental pathways.....	171
6.7.2.2 Topic 2: Understanding common cultural myths about ASD and child development	172
6.7.2.3 Topic 3: The value of the parent-teacher partnership in educating a child with ASD	173
6.7.2.4 Observation: Benefits of empowering parents and professionals	174
6.7.3 Reflection and learning: What next after learning?	175
6.7.3.1 Gaps observed during the workshop and pre-planning for the next action cycle	177
6.8 Action Cycle 4: Lift as you rise.....	178
6.8.1. Plans: All roads lead somewhere	178
6.8.2 Action: God has given us these children	178

6.8.3 Observation: We are human, and we can be flexible	180
6.9 Action Cycle 5: We need to publish our stories and reach a wider community	182
6.9.1 Plans: The world must know about ASD	182
6.9.2 Action: The power of media houses as tools for social change	182
6.9.3 Observation: Our stories are impacting the wider community	183
6.9.4 Reflections and learning: The emancipatory and advocacy journey begins now	183
6.9.4.1 Thinking through the empowerment process	184
6.9.4.2 We are no longer disempowered	184
6.10 Summary of the chapter	185
CHAPTER SEVEN THESIS BUILDING: DISCUSSION AND INTERPRETATION OF THE FINDINGS	186
7.0 Overview of the chapter	187
7.1. Action 1: Parents creating a common identity with one love and one heart: Drawing on traditional support	189
7.2 Action 2: Upsetting the apple cart – reconfiguring relationships with community and formal services providers	197
7.3 Action 3: Building bridges of the partnership between parents and professionals	202
7. 4 Action 4. Lift as you rise	208
7.5 Action 5: Back to the roots: Creating ASD awareness in the broader community	211
7.6 Summary of the chapter	213
CHAPTER EIGHT	215
PUTTING TOGETHER ALL THE STRANDS OF THE EAGLE’S NEST	215
8.0 Overview	215
8.1 Section one: Implications of the thesis	215
8.2 Revisiting literature to relate the previous findings to this study	215
8.3 Methodological and theoretical reflections	218
8.3.1 Methodology perspective	218
8.4 Section two: Reflecting on my journeying of wearing different hats	219
8.4.1 Reflection on the data collection tools	220
8.4.2 A reflection on how data was analysed	222
8.5. Theoretical perspective reflexivity	223
8.5.1 Bronfenbrenner Bio-Ecological System levels	223
8.5.2. Critical-emancipatory theory	225
8.6. Transferring the PAR knowledge to my family empowerment	226

8.7. Section three: Limitations, recommendations, and conclusion of the study.....	228
8.8.1 General recommendations	228
8.8.2 Ten pillars of recommendation to strengthen access to quality support services in Zambia.....	228
8.8.3. Specific recommendations for institutions	338
8.8.3.1. Increasing ASD awareness in the broader community	338
8.8.3.2. Education Sector: Revisiting how education is provided to ASD children	338
8.8.3.3. Health sector: Need for a paradigm shift on how health services are provided to ASD children.....	339
8.8.3.4. Social welfare Sector: Promotion of equity	341
8.8.3.5. Traditional healers	341
8.8.3.6. Religious leaders.....	341
8.9. Limitations of the study	342
8.10 Future research study areas	343
8.11. Conclusion of the thesis	344
REFERENCES	345
APPENDICES	389
Appendix A: Ethics Clearance Letter from the University of Cape Town	390
Appendix B: Ethics Clearance from Ministry of Health Agency-ERES.....	391
Appendix C: Authorisation Letter from the National Health Research Authority	392
Appendix D: Authorisation Letter to use the Assessment Centre for Data Collection	392
Appendix E: Authorisation Letter to Use ZAMISE Assessment Centre	395
Appendix F: Authorisation Letter from the Provincial Education Officer.....	396
Appendix G: Authorisation Letter from Provincial Health Director	397
Appendix H: Invitation Letter to Stakeholders Meeting on ASD Family Needs	397
Appendix I: Focus Group Guiding Rules	398
Appendix J: Information Sheet for Parents.....	400
Appendix K: Informed Consent Form for Parents (Phase One)	406
Appendix L: Informed Consent Form for Parents (Phase Two).....	407
Appendix M: Information Sheet for Professionals (Phase One).....	410
Appendix N: Consent Form for Professionals (Phase One)	414
Appendix O: Interview Schedule for Families (Phase One).....	416
Appendix P: Interview schedule for Families (Phase Two)	423

Appendix Q: Interview Guide for Professionals	425
Appendix R: Attendance Register.....	430
Appendix S: Human Ethics Course.....	431
Appendix T: Newspaper Article	432

OPERATIONAL DEFINITIONS

Advocacy: Influencing decisions, ending assumptions, getting better services, being treated equally, being included, protecting from abuse, redressing the balance of power, becoming more aware of exercising the rights (Dunning, 1995, p. 11).

Community capacity building: The interaction of human, organisational, and social capital existing within a given community that can be leveraged to solve collective problems and improve or maintain the well-being of a given community. It may operate through informal social processes and/or organised efforts by individuals, organisations, and the networks of association among them and between them and the broader systems of which the community is a part (Chaskin, 1999, p. 4).

Community support: Assistance that is given to the family by the wider community where they live or with whom they associate. The support could be informal or formal (Kelly, Ghalaieny, & Devitt, 2012).

Coordinated services: Material resources and services offered by professionals to support families using the multi-disciplinary family support models (Bower Russa et al., 2015).

Empowerment: A group-based, participatory, developmental process through which marginalised individuals and groups gain greater control over their lives and environment, acquire valued resources and basic rights, and achieve important life goals, and reduce societal marginalisation (Maton, 2008, p. 5).

Parent support programmes: Community-based initiatives designed to promote the flow of resources and supports to parents that strengthen functioning and enhance the growth and development of young children (Trivette & Dunst, 2014, p. 1).

Family/parent: Any caregiver who lives with, cares for, prepares, educates, and provides impact survival skills in children to live in harsh environments. A parent/family teaches the child how to create unity in the community, to perpetuate cultural heritage, inculcate feelings of group supremacy, promote communal living and prepare the young for adult roles and responsibilities (Nsamenanga & Tchombe, 2011).

Parent-professional collaboration: A relationship that develops between parents and professionals to help find a solution to a challenge that affects the welfare of the child (Blair et al., 2011).

Participatory action research: A philosophical approach to research that recognises the need for persons being studied to participate in the design and conduct of all phases (e.g., design, execution, and dissemination) of any research that affects them (Vollman et al., 2004, p. 129).

Self-determination: A combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour free from undue external influence or interference (Field & Hoffman, 1999).

Traditional healers: A group of health care providers that are largely unregulated, independent providers who perform health care services in the community (Audet et al., 2020, p. 2).

ABBREVIATIONS

ASD	Autism Spectrum Disorder
CSO	Central Statistics Office.
DIC	Developmental Intervention Clinic
GRZ	Government of Republic of Zambia
MOCDSW	Community Development and Social Welfare
MOD	Ministry of Defence
MOE	Ministry of Education
MOH	Ministry of Health
PAR	Participatory Action Research.
UCT	University of Cape Town
UN	United Nations
UNICEF	United Nations International Children Emergency Funds.
UNZA	University of Zambia
UTH	University Teaching Hospital
WHO	World Health Organisation
ZAMISE	Zambia Institute of Special Education

LIST OF TABLES

Table 4.1: Demographic description of parents.....	80
Table 4.2: Biographical data of professionals	83
Table 4.3: Phase 1 focus group discussions conducted.....	85
Table 0.4: Phase 1 focus group discussions conducted.....	89
Table 5.1: Participant’s identifiers	104
Table 5.2: Structure of theme 1 including sub-themes and categories	106
Table 5.3: Structure of theme 2, including sub-themes and categories	121
Table 5.4: Structure of theme 3, including sub-themes and categories	132
Table 6.0 showing biodata summary of participants in Phase.....	146
Table 6.1: Description of action learning meetings	149
Table 6.2: Summary of Action Cycles benefits to parents support groups.....	153

LIST OF FIGURES

Figure 0-1: Symbol of an Eagle.....	xxiii
Figure 1-1: Map of Zambia showing its location in Southern Africa.....	4
Figure 1-2: Structure of the study.	16
Figure 4-1: Action research spirals.	63
Figure 4-2: Structure of the chapter	64
Figure 4-3: The action research cycles	74
Figure 4-4: Map of Lusaka Province and the districts where the studies were conducted .	77
Figure 4-5: A photo depicting the researcher with participants during a focus group session.	88
Figure 4-6: Parents’ brainstorming activities	93
Figure 5-1: Eagles rearing their young.....	102
Figure 5-2: phase 1 themes, sub-themes and categories	105
Figure 6-1: Showing empowering action cycle	152
Figure 6-2: A poem by parents	160
Figure 6-3: Photos of the parent-led support group.....	170
Figure 6-4: Parents demonstrate how they can play with a child.....	177
Figure 6-5: ASD Awareness materials.....	180
Figure 7-1: Parents likened to noble eagles.....	186
Figure 7-2: Parents’ empowerment process	188
Figure 8-1: Teaching survival skills.	220
Figure 8-2: Pillars of hope for a sustainable ASD programme in Zambia.....	221
Figure 0.3: Illustrating parents as strong and resilient parents.....	223
Figure 0.4: Teaching my son survival skills.....	226
Figure 0.5 Pillars of Hope for a sustainable ASD programme in Zambia.....	229

ABSTRACT

Globally, there has been an escalation in the number of children diagnosed with autism spectrum disorders (ASD). Despite the high prevalence rates, formal and informal support services for children with ASD in lower and middle-income countries are inadequate due to several challenges. This study was conducted in the Lusaka province of Zambia among families of children with ASD and professionals who provide ASD services. The aim of this study was threefold; first, to understand caregivers' experiences with formal and informal support services; secondly, to assess the availability of support services to families of children with ASD and, thirdly, to explore the value of empowering families to meet their support needs through the Participatory Action Research approach. To achieve the aims, the study employed the qualitative Participatory Action Research (PAR) approach as the study design. A total of 76 participants were purposively sampled from both rural and urban contexts.

The study was divided into two phases with phase one focusing on an inquiry into the nature of the problem while phase two was planned for action. In phase one, a total of 73 participants were recruited— 50 community members and 23 professionals. The 50 parents participated in nine focus group discussions (FGD) while in-depth interviews were used to collect data from the 23 professionals using a semi-structured interview guide. Phase two activities included the five action cycles in which 17 parents participated and formed a parent-led support group. The five action cycles were as follows; action cycle one—forming a parent-led support group; action cycle two—being involved in ASD awareness campaigns in empowering specific professionals in higher institutions of learning; action cycle three—capacity building on how to educate a child with ASD; action cycle four—being involved in ASD awareness in rural areas to empower the less empowered parents and professionals; action cycle five—taking back the ASD awareness advocacy to the broader community through publishing their stories in print media.

These parents worked together for ten months to address the identified barriers to ASD support services as observed in phase one. Verbatim transcription was used, and data was analysed thematically. Based on analysis of this data from the participants, themes were distilled through the interpretive description. The key findings in the study revealed that

parents face many barriers in accessing formal and informal support services. These barriers were compounded by a scarcity of knowledge about ASD at the parent, professional, and community levels. ASD diagnosis and treatment included exploring religious, traditional, and western medical treatments. The study found that the ASD diagnostic tools used to confirm ASD diagnosis were not uniform and were often used by poorly trained professionals.

Parent-initiated support groups appear to be a positive mechanism to promote ASD awareness in both rural and urban settings. Through a parent-led support group, participants gained important empowerment skills as well as a better understanding of barriers to their children's unmet needs. Parents were enabled to develop self-empowerment skills and be more proactive in bringing social change to the community and homes.

Parents, therefore, should participate in finding a solution to address barriers to support services as they are essential stakeholders in service delivery. The absence of support services may mean that parents will continue experiencing high-stress levels and remain disempowered. The role of support groups as a mechanism to foster a sense of empowerment within members needs to be acknowledged.

There is a need to develop affirmative ASD policy frameworks that support access to appropriate services. Further studies need to extend our understanding of how parents' involvement in PAR methodologies can be used to empower and shape the nature of services that they require in low and middle-income countries.

PREAMBLE: A JOURNEY WITH EXPERIENCE



Figure 0-1: Symbol of an Eagle

The Symbol of an Eagle represents parents' self-empowerment process of bringing social change to the unmet needs of their children with ASD (This picture is with the courtesy of Mphatso Nyoni, our last-born son aged 11 years).

Living with people with disabilities: The game changers

As I reflect on my academic life and religious journey, I have come to realise that I have lived most of my life interacting with people with disabilities and advocating for the rights of persons with disabilities and marginalised groups. Later in my life, little did I know that we would have a son diagnosed with ASD. These personal experiences have motivated me to understand what it means to be a parent of a child with a disability. Five experiences in my life's journey have led me to define disability from a social, religious, and human rights advocacy perspective.

My first, social, religious, and human rights advocacy experience took place in the 1980s during my high school days. This was the time when I found myself sharing a table with a person with albinism. The table used to accommodate a maximum of ten pupils sharing one dish of food. However, no one wanted to associate or eat with a student with albinism because of his bleeding gums. I was having this experience with a background of coming from a missionary environment that had two worlds, one for persons with leprosy and the other for the non-leprosy community. I used to wonder why persons with leprosy were discriminated against and lived isolated lives. However, over time, I saw the missionaries slowly integrating persons with leprosy into the mainstream. I expected the same at high school.

The second experience was during my college years in the late 1990s whilst at Nkrumah, University College. Between 1998 and 1999, I found myself again spending most of my time assisting my friend with a physical disability who had challenges walking to the classroom. We would take over 20 minutes to cover approximately 50 meters which was the distance from the hostels to the university. He was determined to pursue his studies. Later, we met at the University of Zambia where he pursued his degree. Today, he is one of the Senior Education Officers in the Ministry of General Education in Zambia.

The third experience was in late 2010 when I shared an apartment for two years with a person with visual impairment. His name is Thomas Mtonga. Thomas was given this apartment by the University of Zambia as a student fellow. I lived with him in his apartment for two years together with a colleague Joseph Simfukwe during my master's degree programme. During my stay, I learned a lot about persons with disabilities barriers and their resilience to survive and live independent lives. I knew Thomas during our undergraduate studies. He already had a diploma and degree in teaching, and he was pursuing his master's degree. He was a determined person. The University of Zambia library had no braille books, so I would collect books for him from the library. I used to read parts of the book to him, and he would write what I read for him on his computer, fitted with speech computer software. Thomas defied all odds and did very well at an undergraduate level. He became the first visually impaired person to be taken on as a Staff Development Fellow (SDF), despite not meeting the age limit criteria as he was above the age limit. Thomas is the first visually impaired person to be employed by the University of Zambia as a lecturer.

The fourth experience involved a lady who was my fellow student at the University of Zambia. Georgina Mumba used a wheelchair to remain mobile. She was the first disabled woman to serve on the University Union Executive Committee. I became her campaign manager, and she was victorious in the election. I still can remember lifting her so she could ascend the stairs to the top in the student hostels because the university hostels have no lifts. Today, Georgina is an ardent disability inclusion advocate, an award-winning disability inclusion champion and one of the Senior Officers in the Social Protection Sector in Zambia. Collectively, these experiences ignited in me the strong desire to fight for social injustices at higher institutions of learning such as the University of Zambia.

The last and most painful experience was learning that my only son was diagnosed with ASD at the age of five. Three episodes stood out during the pre-and post-child diagnosis of our son. Firstly, there was the burden of travelling long distances (over 800km), three to four times a month for four years. This was the time when we were seeking to find ASD services, which were only in the Lusaka district. Secondly, I can clearly remember the harrowing experience of sharing the same bed in the hospital for five days when he was admitted for further investigation. I still remember carrying my son to the surgical theatre at the UTH hospital, over 200 meters because the nurses could not manage to control his hyperactive behaviour. Thirdly, we needed to search for his special early childhood education. This was another experience that forced me to relocate from a rural setting to the Lusaka district.

All these experiences generated a lot of questions like; What is it like to have a child with ASD in Zambia? What type of services is available for ASD parents? From 2009 to 2011, I did my master's degree in ASD. I explored the impact on a caregiver or parent after discovering that a child has ASD. The study took a phenomenological approach. It highlighted a lot of gaps in what it means to discover that a child has ASD. The gaps included a lack of support services for parents of children with ASD.

My experience of working as a lecturer at the Zambian Institute of Special Education (ZAMISE), mostly in the assessment centre and monitoring and evaluating how special education is provided in the country enabled me to fill a void in my life. I observed that almost all parents who came to access ASD services had similar complaints about the limited availability of ASD support services.

My research assumptions were that:

- Parents think that they know about ASD services and barriers to support services.
- Equally, professionals believe they know about the experiences regarding children with ASD as they provide the services.
- Parents of children with ASD are the most oppressed and disempowered group in the community in accessing formal and informal support services.
- There is inequality in how ASD services are provided to children with ASD.
- The use of parent-led support groups can be used as an empowerment strategy.
- The researcher and the subject can be co-learners during the research study.
- Local people know their environment best and have innate knowledge about the phenomena affecting them. They can analyse, plan, implement, and evaluate their projects.
- Sharing of lived experience stories is part of therapy and can promote critical thinking and emancipation in parents.
- Parents have power like an eagle to protect, defend and provide unmet needs to their children with ASD.
- The Health treatment and rehabilitation of a patient should not only consider the anatomy and physiology (medical) but more importantly, the psychological treatment and rehabilitation.

These research assumptions led to the formation of a thesis entitled *A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services Available Among Zambian Families of Children with Autism Spectrum Disorders*. I felt that the use of qualitative methodology was appropriate because I would be able to listen to parents' multiple realities and gain more insight into their experiences in accessing formal and informal support services. Furthermore, the qualitative participatory action research (PAR) approach was ideal as parents were able to identify their problems, share the challenges, plan, act and evaluate the activities.

I drew my practical principles to conduct PAR research from the Bible verse in 1 Corinthians 13 (New International Version 1984) which states that:

If I speak in the tongues of men or angels but do not have love, I am only a resounding gong or a clanging cymbal.

² *If I have the gift of prophecy and can fathom all mysteries and all knowledge, and if I have a faith that can move mountains, but does not have love, I am nothing.*

³ *If I give all I possess to the poor and give over my body to hardship that I may boast, but do not have love, I gain nothing.*

⁴ *Love is patient, love is kind. It does not envy, it does not boast, it is not proud. ⁵ It does not dishonour others, it is not self-seeking, it is not easily angered, it keeps no record of wrongs.*

⁶ *Love does not delight in evil but rejoices with the truth.*

⁷ *It always protects, always trusts, always hopes, always perseveres.*

⁸ *Love never fails. But where there are prophecies, they will cease; where there are tongues, they will be stilled; where there is knowledge, it will pass away.*

⁹ *For we know in part, and we prophesy in part,*

¹⁰ *but when completeness comes, what is in part disappears.*

¹¹ *When I was a child, I talked like a child, I thought like a child, I reasoned like a child. When I became a man, I put the ways of childhood behind me.*

¹² *For now we see only a reflection as in a mirror; then we shall see face to face. Now I know in part; then I shall know fully, even as I am fully known.*

¹³ *And now these three remain faith, hope and love. But the greatest of these is love.*

Every time I looked into the mirror; I could not see my image but the gaps in the image of parents with ASD who are shunned by the community because of having a child with ASD. I saw myself imaged been marked with social injustices. Therefore, I needed to practice love and not only talk about love/Charity. This love could be shown by working with parents of children with ASD. I have noticed that every time, we took our child to the hospital, I could not see the love from medical doctors and other health professionals. I could not see the love of trying to heal our emotions of the child and that of my family using psychological treatment and rehabilitation. Doctors felt they could heal our wounds

by concentrating in diagnosing the condition and providing medicine to the child rather than also providing psychological well-being of the family.

My Statement of personal reflexivity.

My long journey of conducting this research using the PAR approach was in the initial stage filled with fear of failure to use the methodology correctly. The fear was more in the initial stage of designing the research study.

The cause of fear was compounded with limited publications in Africa that have used the PAR approach to investigate challenges faced by parent of children with ASD in accessing formal and informal support services.

Another fear was the anticipated number of participants who could drop-out of the study as it progressed. Before, I could even start the study, I considered the length of time that parents were expected to work with me (10 months).

I was aware that some of the parents were in formal employment, and they could face challenges getting permission at work to attend the meetings. I was equally worried of the economic losses parents could experience in the coming 10 months. I did not know whether parents could choose to remain in the research or opt for economic activities.

The last and greatest fear was based on the strong culture and customs beliefs mostly among the older generation who could still be holding strong beliefs that a woman should not share personal experiences with men they don't know. I was not sure if older grandparents, mothers from rural areas and peri-urban could freely share their lived stories about the pre-pregnancy, peri and post-natal experiences.

However, I observed that from the initial stage of engaging the parents, they were ready and willing to participate in the study. I have conducted several research studies and some published in journals. However, the use of PAR approach was quite different as it was more of participants' self-driven and self-motivating. This proved to me that PAR methodology was ideal for this study. See Chapter 8 for detailed personal reflexivity.

Therefore, engaging in this thesis was not only about getting a degree and pursuing a personal achievement agenda but also about bringing social change into the lives of the Zambian community from a human rights, social and religious advocacy perspective.

CHAPTER ONE:

INTRODUCTION

1.0 Background of the Thesis: Setting the Scene

That was one of the most shattering experiences in my life because I lamented to God, saying that: 'God if it were possible, I would put back my son in the womb because that is the only place where you know not any rejection will come from' (Parent: FGD7 P3).

1.1 Overview

This thesis focuses on the challenges that parents of children with Autism Spectrum Disorder (ASD) experience in accessing support services. It also highlights how Zambian parents of children with ASD identify the ASD barriers and act to address them. The quote above (Parent: FGD7 P3) gives a summary of parents' experiences with current support services. For this thesis, autism and ASD are terms that are used interchangeably to refer to autism spectrum disorders (ASD). Similarly, terms like 'parents of children with ASD' and 'families of children with ASD' are used interchangeably in this thesis to refer to the same group of people.

In many collectivistic societies like Zambia, a child's birth brings joy to the family and celebration to the whole community. In Zambian settings, no person celebrates the birth of a child alone; the whole community takes part in the celebrations. This is because the village (community) belongs to the child and the family belongs to the village. No person exists on his or her own. Mbiti states:

In traditional life, the individual does not and cannot exist alone except corporately. He owes his existence to other people...The community must therefore make, create or produce the individual...Only in terms of other people does the individual become conscious of his being, his duties, his privileges, and responsibilities towards himself and other people (Mbiti, 1969, p. 108).

However, such joy can be short-lived if a child is discovered to have a disability. This is because having a child with a disability can be received with different responses and reactions and mixed feelings from both the parents and the community. Many parents

receive the news with shock, surprise, fear, and grief and it elicits some troubling feelings within the parents (Cloete & Obaigwa, 2019; Gona et al., 2016). The stressful situation in parents is exacerbated by the limited knowledge at pre-, peri- and post-diagnosis regarding treatment, care and raising a child with a disability. These strongly, negatively oriented emotional reactions require adequate follow-up services with formal and informal support (Banach, Iudice & Couse, 2010) to help families deal with the burdens presented by the situation (Harper, Dyches, Harper, Roper, & South, 2013; Smith & Anderson, 2013).

Parents of children with severe to profound intellectual disabilities reported high burden levels even in adulthood due to a lack of independence and reliance on caregiver support (McKenzie, 2014). Further studies have shown that over 50% of parents aged 50 years and above still live and care for their children with developmental disabilities compared to 17% of parents raising typical children (Seltzer et al., 2001). Families of children with ASD are the most stressed and affected group as compared to those without (Falk et al., 2014). There was a need to conduct a study in Zambia among ASD parents to explore how parents dealt with issues of stress and childcare.

Studies have shown that families that receive early knowledge about ASD and access to early intervention services have better outcomes for their children (Landa, 2018; Muller & Cannon, 2014). However, families that delay in accessing early intervention services experience greater burdens with a high rate of dependency on support even in adult life (Müller & Cannon, 2014). To minimise stress and mental health problems, parents require a lot of support (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Pruitt, Willis, Timmons, & Ekas, 2016; Samadi, McConkey, & Kelly, 2012; Weiss, Wingsiong, Lunskey, 2014). Additionally, such a helping hand can be provided as formal or informal support services.

Available literature in Zambia on access to services by children with disabilities revealed that families of children with disabilities face various barriers to access support services (Chansa-Kabali et al., 2019; Macha et al., 2020; Washington-Nortey & Serpell, 2021; Wonani & Muzata, 2019). Some of the barriers include long queues and waiting times for appointments to visit the doctor, a poor attitude by professionals such as teachers, medical officers, and policemen towards parents of children with ASD (Nyoni & Serpell, 2012), limited ASD awareness, (Chansa-Kabali et al., 2019), lack of an ASD family support group in the community (Wonani & Muzata, 2019), limited resources to support families (Hansen et al., 2014; Halwindi et al., 2013), distance to health care facilities (Halwindi et al., 2013),

non-uniformed diagnosis tools and shortage of ASD diagnosis and treatment services (Nkole, 2017). Literature from Zambia discussed here is not exclusively about children with ASD, but on access to health services and more generally on children with various disabilities.

Putting in place formal and informal support systems, and empowering parents to use parent-led support groups through the PAR approach could help deal with challenges mostly in communities that have a shortage of qualified professionals (Rockers et al., 2016; World Health Organisation, 2010). Formal support should be provided by professionals (Boyd, 2002) and informal support services by family members, friends, and neighbours through social and emotional activities (Harper et al., 2013; Kelly, Ghalaieny, & Devitt, 2012). Formal and informal support services to parents have proven to be useful in improving the quality of life for parents of children with ASD (Boyd, 2002). There is a need to investigate the type of formal and informal support services provided to children with ASD and their parents in Lower and Middle income nations.

1.2 Context of the study

This study was conducted in Zambia, Lusaka Province among families raising children with ASD in urban and rural settings. Zambia is a landlocked country in Southern Africa with a land size of 752,000 km² (see Figure 1.2). Zambia has a current population of 17,807,357 with 22 languages and 72 dialects. The official language is English and it is used alongside seven official local languages: Bemba, Kaonde Lozi, Luvale, Lunda, Tonga, and Nyanja (The Government of the Republic of Zambia, 2010).

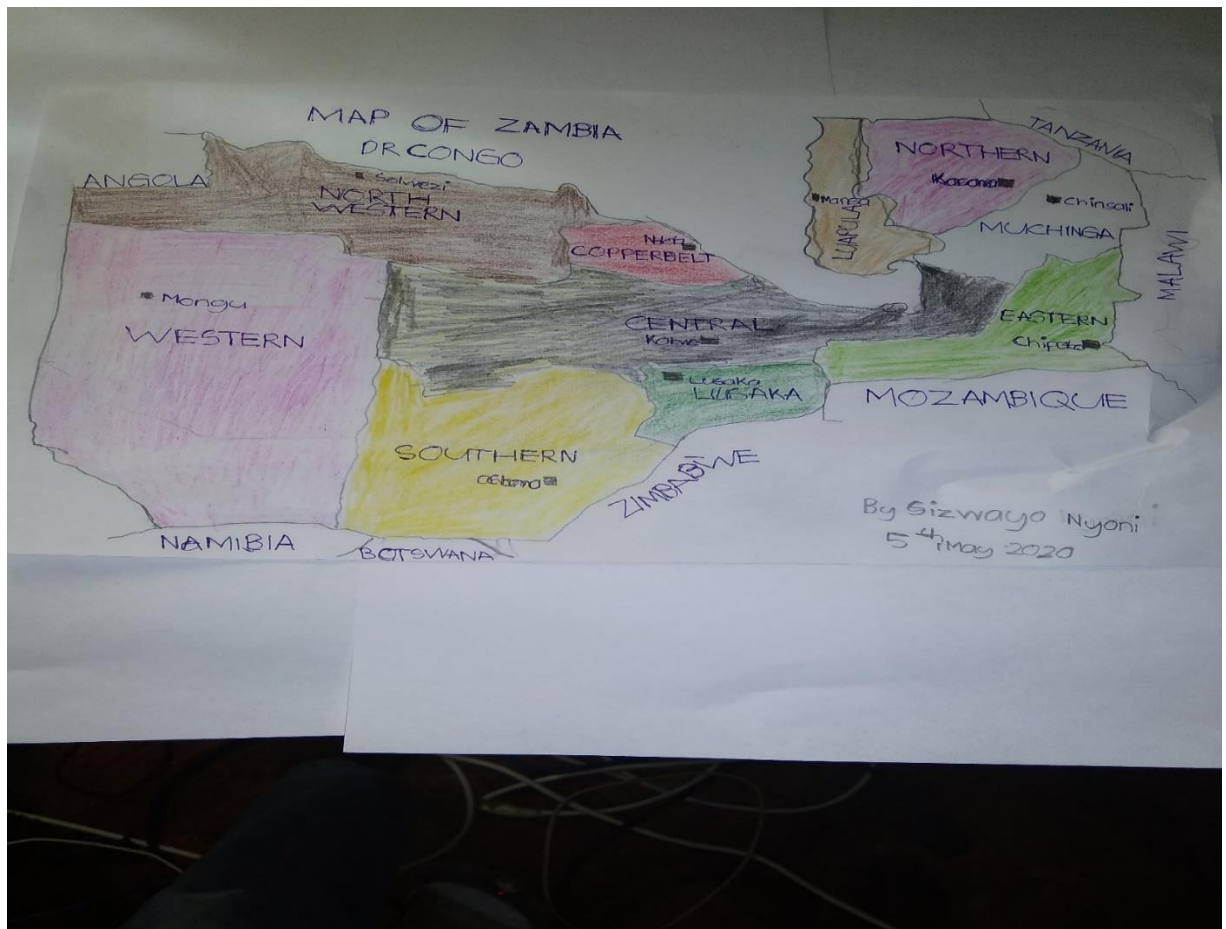


Figure 0.1: Map of Zambia showing its location in Southern Africa

The map was drawn and scanned by my second-born Sizwayo Nyoni, a Grade 9 pupil who was diagnosed with ASD when he was five years.

In terms of Zambia's economy, the indicators show that the Zambian economy has for years been unstable and has not performed well. The poverty levels are still high, and this is a big problem among many Zambians, mostly those in rural areas. About 59% of Zambians are living below the poverty line (The Government of the Republic of Zambia, 2012a). According to the World Bank report, 77.9% of the rural population and 27.5% of those in urban areas live in poverty (The World Bank, 2015). This scenario even now is more challenging to families of children with disabilities (Malungo et al., 2018). This is because some families in the informal sector depend on some pieces of work by selling vegetables and fruits for their livelihood (Magnusson, 2011). Consequently, economic hardships at both household and national levels cause parents to find it challenging to access quality education and health services as they use out-of-pocket money to pay for the services. Studies have shown that poverty has implications for health and education.

For instance, children from poverty-stricken households are more likely to suffer from various forms of disabilities (World Health Organisation (WHO), 2011) and likely not go to school and access quality services (The Government of Republic of Zambia, 2010). This includes parents of children with ASD in Zambia.

There are limited publications in Zambia analysing parents from poverty-stricken and middle-class households and even those from affluent families on how much funding a child with ASD and their family requires each year to care for such a child. This is in contrast with the United Kingdom (UK), where the government spends over £2.7 billion each year to support ASD families and children (Knapp et al., 2009). The United Kingdom spends over £1.23 million on each child with ASD across their life span (Knapp, Romeo, Beecham, 2009). However, in fragile economies like Zambia which has no ASD national budget line as it cannot meet the costs of supporting the needs of both the parents and a child with ASD, can use of other effective low-cost strategies such as the promotion of parent-led support groups could be beneficial to both the parents and the community. This is because Zambian parents of children with ASD struggle to access adequate services such as health services (Chansa-Kabali et al., 2019). This is because of many factors such as the high costs to accessing the services and this is coupled with the poor doctor and nurse to population ratios at 1:15,000 and 1:1,500, respectively (Makasa, 2009). Other barriers include insufficient national budget funding to the Ministry of Health. As of 2016, only 8% of the national budget was allocated to the Ministry of Health (The Government of Republic of Zambia, 2018) and the trend has been the same; even in 2021 the annual national budget allocated only 8.1% to the Ministry of Health (The Government of Republic of Zambia, 2021). This has resulted in parents using out-of-pocket money to meet other costs since the unit costs of accessing health services at an individual level were very high. For example, the out-patient services unit costs at a third-level hospital were not less than 14 USD. The cost excluded the cost of medical consumables (The Government of the Republic of Zambia, 2018). Such costs were prohibitive and beyond an ordinary person's capacity to afford them.

Parents equally experience challenges in accessing quality education for their children with ASD. The most affected learners are learners with disabilities in rural areas (Malungo et al., 2018). Studies have shown that over 113,000 children with disabilities were school dropouts (Ndhlovu et al., 2016). This is despite primary education being free (Parnes et al.,

2015; The Persons with Disabilities Act, 2012) and the introduction of programmes such as home-grown school meals programmes in some schools to improve the children's nutrition status and motivate children to go to school (The Government Republic of Zambia, 2020).

Another unmet need of parents of children with ASD had to do with limited published studies on the specific ASD policies and social services provided by the Ministry of Community Development and Social Services, a ministry responsible for issues of disability with parents of children with ASD. The people who benefit the most are families of a person with physical impairments, the vulnerable and aged persons. There is no publication in Zambia that has looked at the role of social welfare officers in supporting families of children with ASD.

This study sought to bring to light the perception Social Workers have towards children with ASD. To address such unmet needs of parents of children with ASD, this study took the cost-effective and cultural context of a community-based rehabilitation approach that engages the local people who are affected by the phenomenon. In this study, I wanted to explore how parents of children with ASD would identify their challenges and find a solution to them within a cultural context. A PAR methodology was selected because studies have shown that the community-based rehabilitation approach have proven to be more cost-effective in lower- and middle-income nations. For example, studies have been conducted in Southern part of African. A study conducted South Africa among women with disabilities (Lorenzo, 2005), another in Zambia by Rockers et al. (2016, 2018) who observed improvement in early childhood development among rural parents and in Zimbabwe by Hope & Timmel (1986). All those studies showed the benefits of PAR methodology. This approach could be effective in countries like Zambia that faces many barriers and hindrances to ASD support services.

1.3 PAR approach among Zambian parents of children with ASD

This study was motivated by the limited research studies in the global South relating to evidence-based studies on the ASD family's interventions that uses the PAR approach. Many studies have looked at experiences of parents of children with ASD which have used the traditional research methods, whereby the affected groups are not involved in identifying the challenges but the members are seen as receivers of knowledge and not knowledge generators (Bromley et al., 2004; Frye, 2016; Munroe et al., 2016). The PAR

methodology was employed in this study because of its robust outcomes when used in family-centred interventions in which the community works as a team to resolve issues affecting them in their respective communities (World Health Organisation, 2010). This study adds to the few publications on family support services using the PAR approach. PAR approach is used as an alternative strategy to give power to marginalised groups. The PAR empowerment process is controlled and managed by parents themselves. It provides the most needed support to human beings of having psychological healing which might not mostly provided by some health professionals. This can be done through reflective action learning meetings.

1.4 The theoretical frameworks guiding the study

The theoretical frameworks selected are Critical-emancipatory and Bronfenbrenner's Bioecological frameworks. Using the Critical-emancipatory theory, parents in this study were able to use their newly acquired abilities to identify their own challenges, act on the barriers, talk back and stand up for their chosen position regarding the current ASD services. This was done through dialoguing with professionals, community members and fellow parents of children with ASD. The skills gained through Critical-emancipatory theory resulted in parents to interrogate sources of information, empower each other socially, emotionally, financially and form a support group to promote ASD awareness.

The use of the Bronfenbrenner's Bioecological frameworks guided parents to appreciate the importance of sharing their challenges at ecological systems levels in their respective environments. The first was at micro level. In Phase 1 only parents of children with ASD were involved in FGD. Later parents took the awareness messages to other ecological system levels at macro, meso and chrono levels. It was at different Bioecological systems levels (Action Cycles) were parents empowered each other with knowledge and skills. After this, parents had to negotiate power imbalances with professionals and collaborated with professionals. Finally, parents took the ASD awareness message to the wider community (See Chapter 6).

The chosen theories are appropriate for the current study because they carried with them empowerment principles whereby data collections were done by participants in naturalistic settings and followed the qualitative approach (See chapter 4).

1.5 Significance of the study: Research and theory

Understanding the experiences of parents of children with ASD as they sought support services and addressed the identified barriers using the parent-led support group has potential implications for the fundamental conceptualisation of well-being for the concerned population. To my best knowledge, this study is the first research to have had parents of children with ASD providing their first-person accounts in answering the question of what it means to be a parent of a child with ASD in Zambia. This study will help researchers and policymakers to be sensitive and to reflect on the barriers to support services that parents experience in their respective communities.

The use of PAR is consistent and in line with the World Health Organisation policy with a call to autism researchers to increase involvement and collaboration with the local communities to address their real-life concerns (World Health Organisation, 2010). This is because PAR allows the local voice to be heard and appreciated by researchers. The insights from this thesis will inform how future researchers can better facilitate active research participation of families of children with ASD in low-cost communities. In addition, this research study could further help our understanding of the benefits of parent-led support groups.

1.6 Significance of the study: Research and practice

The findings from this study might contribute to an understanding of how ASD services are provided in low middle-income countries (LMIC) and how to address the identified barriers by getting the affected group involved, motivating them to act together to brainstorm solutions. The experience from this study could be useful to policymakers, parents of children with ASD, and other stakeholders. Applying PAR to disability studies can contribute to the articulation of the theory on the relationship between health and empowerment. Furthermore, the results of this research experience might ignite other researchers in the future to conduct similar studies in their cultural context.

1.7 Research problem

The disability prevalence rate is on the increase. Global statistics indicate that over 1.86 billion children under the age of 15 had a disability (World Health Organisation, 2011) and one in 160 children globally are children on the autism spectrum (World Health Organisation, 2013b). ASD is equally on an increase in Africa, Zambia inclusive (Abubakar, Ssewanyana, & Newton, 2016; De Vries, 2016). This calls for investment in

ASD services that will meet the demand that comes with the increase of children with ASD in the nation. Zambia needs to invest in laws and policies that promote human rights, give legislative guarantee for budgetary allocations, and invest in human resource development and ASD diagnosis and treatment tools.

Considering that Zambia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (WHO & The World Bank, 2011) and has developed its local policies and laws on disabilities, which include the Zambia Person with Disability Act of 2012 (Government of Republic of Zambia (GRZ), 2013), the Seventh National Development Plan (The Government Republic of Zambia (GRZ), 2017), and Educating Our Future (The Government Republic of Zambia, 1996a) There is overwhelming evidence that has shown that informal and formal support services appear to be inadequately addressed (Gow, George, Mutinta, Mwamba, & Ingombe, 2011; GRZ, 2013; Makasa, 2009; The Government of the Republic of Zambia 2011, 2012a; Shen et al., 2017). This is coupled with other barriers such as budget line support included in the national budget on issues of ASD and parents formal and informal unmet support needs (Nyoni, 2011). This is different from developed nations such as the United Kingdom and the USA that have budget support for families and children with ASD (Buescher, Zuleyha, Knapp & Mandell, 2014; Knapp et al., 2009).

The other gap observed in ASD support services was limited data on the provision of respite care to Zambian caregivers. Studies have shown that parents have high expectations for their children with autism which include living independently, attaining training and acceptance and social inclusion of a child with autism by society (Washington-Nortey & Serpell, 2021). There is an equally limited number of studies that highlight the role of father involvement in lower and middle-income nations (Karisa et al., 2020). There was a need for a study to be carried out in Zambia, one that focused on family support services using PAR where both female and male voices and their cultural and traditional diversity would be respected. Such a study should aim at promoting social change for parents, communities, service providers, and policy makers. At the time of this study, many families of children with disabilities in Africa, including Zambia, had not been treated as equal partners in accessing quality service provisions. Many were disempowered in the designing and implementation of programmes that deal with service provision for their children.

To the best of my knowledge, no study has been carried in Africa on considering family support needs for children with ASD using the PAR approach. The only study which used a similar approach was conducted in 2019 by Van der Mark, who explored the well-being and transformation of mothers of disabled children from poor urban settlements in Southern Africa (Van de Mark, 2019). However, her study was based on families with disabilities in general, whilst this research specifically focuses on ASD families. Studies have shown that the involvement of parents in the research study is key to a better understanding of the phenomenon affecting them in their environment (Boehm & Carter, 2016; Samadi, Samadi & McConkey, 2015).

This study might help researchers to understand the use of PAR as a research methodology and how parent empowerment can enhance access to services. Results from this research will help build capacity among the policymakers, non-governmental organisations and civic leaders who have limited knowledge of ASD and family support in Zambia. The study might help teachers and social welfare officers in the planning of the education curriculum for children with ASD. Researchers would be challenged to value local participants as a source of rich knowledge and experts of social challenges affecting their community. In addition, the study will assist medical professionals appreciate the use of both medical treatment and psychological treatment and rehabilitation when dealing with health related issues.

1.8 Research aim

The study aim was to understand the experiences of parents concerning formal and informal support services for families of children with ASD in Zambia and explore ways to address support needs by empowering parents using a PAR approach.

1.9 Main questions

This research was guided by three main questions:

1. How do parents experience formal and informal services available in Zambia and what additional support services would they require and why?
2. What are professionals' experiences in providing formal support services to families of children with ASD, and what future support services would they desire families to access?
3. How does involvement in PAR support parents' empowerment to meet identified unmet needs of their children?

1.10 Research objectives

1. Explore how parents experience formal and informal services available in Zambia and what additional support services they would require and why.
2. Establish professionals' experiences in providing formal support services to families of children with ASD and what future support services they would desire families to access.
3. Understand how involvement in PAR activities support parents' empowerment to meet identified unmet needs of their children.

1.11 Structure of the thesis

This thesis has eight chapters and is structured as follows:

Chapter 1: Setting the scene

Chapter one presents the background of the study, and the context in which the study was conducted. The chapter further discusses the rationale of conducting the study, aims and objectives, its significance, and the key research partners during data collection. This chapter also gives a justification as to why I decided to conduct this study.

Chapter 2: Theoretical frameworks

Chapter two provides the theoretical frameworks of the study. The theories that guided the study include the Critical-emancipatory and the Bronfenbrenner Bio-ecological. The Critical-emancipatory theory originates from the Frankfurt School formed by Western Marxist social researchers from Frankfurt, Germany. This theory considers social justice and the relationship of knowledge, power, and ideology to be at the centre of the learning experience (Habermas, 1971). It focuses on the empowerment of an individual's emancipation and rejects the notion of dehumanising any individual through any means of oppression, human exclusivity in social participation and the idea of human hierarchy when providing services. Freire, as one of the key advocates of the Critical-emancipation theory, supports the notion that a permanent relationship of dialogue between the teacher and the learners should be established (Freire, 1972). Therefore, Critical-emancipatory theory aims to create a relationship between the researcher and the community, and its

focus is to emancipate people from rigid structures of domination. The Critical-emancipatory theory looks at the felt needs of the oppressed person (Freire, 1972).

Bronfenbrenner's Bio-ecological systems theory (Bronfenbrenner, 1994) is a theory that explores an individual's connectedness to the environment and how the co-dependence between the individual and the environment is critical in human development. This theory assumes that activities in the environment impact human actions and behaviours (Bronfenbrenner, 2005; Rosa & Tudge, 2013). The theory further believes that human development is a continuous process through a life span and this behaviour is generally influenced by activities in the local environment. Each individual's interconnected to relationships and the feedback that a person obtains is affected by historical accounts of events and time (Etteka & Mahoney, 2017).

The two theories were used in this current study because they carry social support services and emancipatory principles. Secondly, the theories were appropriately applied in the Zambian cultural context in understanding the unmet needs of Zambian parents of children with ASD.

Chapter 3: Literature review

Chapter three reviews the literature on what other scholars have said about the study. The literature reviewed includes studies that are conducted in other countries and specific studies which were conducted in Zambia. In general, chapter three discusses how ASD is defined, its prevalence rate, the evolution of diagnosis and treatment. The chapter further explains how the term ASD is understood by medical personnel, African traditional healers, and religious leaders. Other reviewed literature considered the burdens of raising a child with ASD, parents' experiences with formal and informal support services, and, lastly, the chapter explains how disability policies are viewed in Zambia.

Chapter 4: Methodology and methods

Chapter four highlights the methodology and methods. This study used a qualitative Participatory Action Research (PAR) approach. The study was divided into two phases: Phases one and two. In Phase one, 73 participants were recruited-50 community members and 23 professionals. Nine focus group discussions (FGD) were conducted with parents, whilst in-depth semi-structured interviews were used to collect data from the 23

professionals. Phase two had 17 parents who volunteered to continue with the study from Phase one. The participants were involved in empowerment activities that resulted in five action cycles, namely: Action cycle one-forming a parent-led support group; Action cycle two-getting involved in ASD awareness campaigns in higher institutions of learning where specific professionals were empowered with knowledge skills about ASD; Action cycle three-capacity building and parents-professional collaboration (this was about parents negotiating for power balance as they enlisted for more knowledge about ASD); Action cycle four-advocacy, and community mobilisation (parents had to empower the less empowered group of fellow parents and professionals); and Action cycle five-taking ASD awareness messages to a larger community through publishing their stories in the print media. These parents worked together to address the identified barriers to ASD support services as observed in Phase one. The chapter further discusses the tools used to collect data, which include interviews, field notes, journaling notes, audio, and video devices. The chapter also explains how ethics clearances, confidentiality and the validity of the study were achieved.

Chapter 5: Identifying the state of the problem: The findings - Part one

The chapter discusses the first findings based on themes and sub-themes generated in Phase one. The key themes generated include juggling multiple sources of ASD knowledge, community and informal support, ASD specific knowledge and formal services. Each theme has three sub-themes and categories. The themes and sub-themes are from the narrative stories of parents' experiences as they sought support services. This was done during focus group discussions with parents in various locations. The other information came from the interviews conducted with professionals in their respective offices. It also includes the experiences of professionals who directly work with families and children with ASD. Similar themes from both parents and professionals are interlinked to give an in-depth understanding of the nature of barriers faced by parents to access ASD services that were available at the time of the study. The findings from interviews in this Phase led to parents identifying some of the key barriers to the unmet needs of the child which were addressed in Phase two. Key barriers to support services included; parents and the community's limited knowledge in understanding of ASD causes, diagnosis, and treatment. This led parents to seek ASD services from various service providers on several occasions from medical professionals, traditional healers, and religious leaders. This was

because there was a limited number of parent-led support groups to provide social-emotional support to parents. Other barriers included the cost of accessing formal support services was very high and not affordable to a common Zambian. Discrimination was one of the major challenge as this led parents live isolated lives because of limited support from the immediate family members and the community. Parents were stressed with child care as they were sole carers. The family members and the community did not know how to provide respite care to a child with ASD. Parents had to find a solution as to how to address the unmet needs as discussed in chapter six.

Chapters 6: Partnership in action: The Findings - Part two

Chapter six discusses the second part of the findings. The findings are based on the actions taken by parents through a parent-led support group. Parents formed a support group to address the identified barriers to support services. The action taken resulted in five action cycles.

Action cycle 1: Forming of a support group.

Action cycle 2: Parents conducted meetings with higher institutions of learning.

Action cycle 3: Parents conducted a capacity-building workshop for building themselves and professionals on how to care for and educate a child with ASD in partnership with special teachers, whilst using locally available materials.

Action cycle 4: Parents conducted ASD awareness meetings in rural areas.

Action cycle 5: Parents had to publish their stories in newspapers to reach a wider readership.

Chapter 7: Thesis building: Discussion and interpretation of the findings

Chapter seven provides the discussion of the findings and describes what it means to be a parent of a child with ASD in lower and middle-income nations, where ASD services are scant, and society has limited knowledge and understanding of ASD. The chapter provides an empowerment story of parents following the action cycles they were involved in. Parents shifted their power from being considered as novices on issues of ASD by professionals to teaching professionals who turned out to be novices. The empowerment

stories further highlight how parents collaborated with professionals to reduce power imbalances, later going to the community to uplift others. These empowerment stories are supported by reviewed literature from both lower- and middle-income nations and developed nations.

Chapter 8: Putting together all the strands of the eagle's nest

In Chapter eight, **Putting together all the strands of the eagle's nest**. This is the last chapter, and it summarises the study. It first gives a summary of the key findings by confirming or disconfirming what other scholars stated about similar studies. The chapter highlights new knowledge that the study has contributed to disability studies from the Zambian context. This is followed by the researcher's reflexivity, limitations of the study, recommendations, and conclusion. Figure 1.2 shows the structure of the study.

STRUCTURE OF THE STUDY

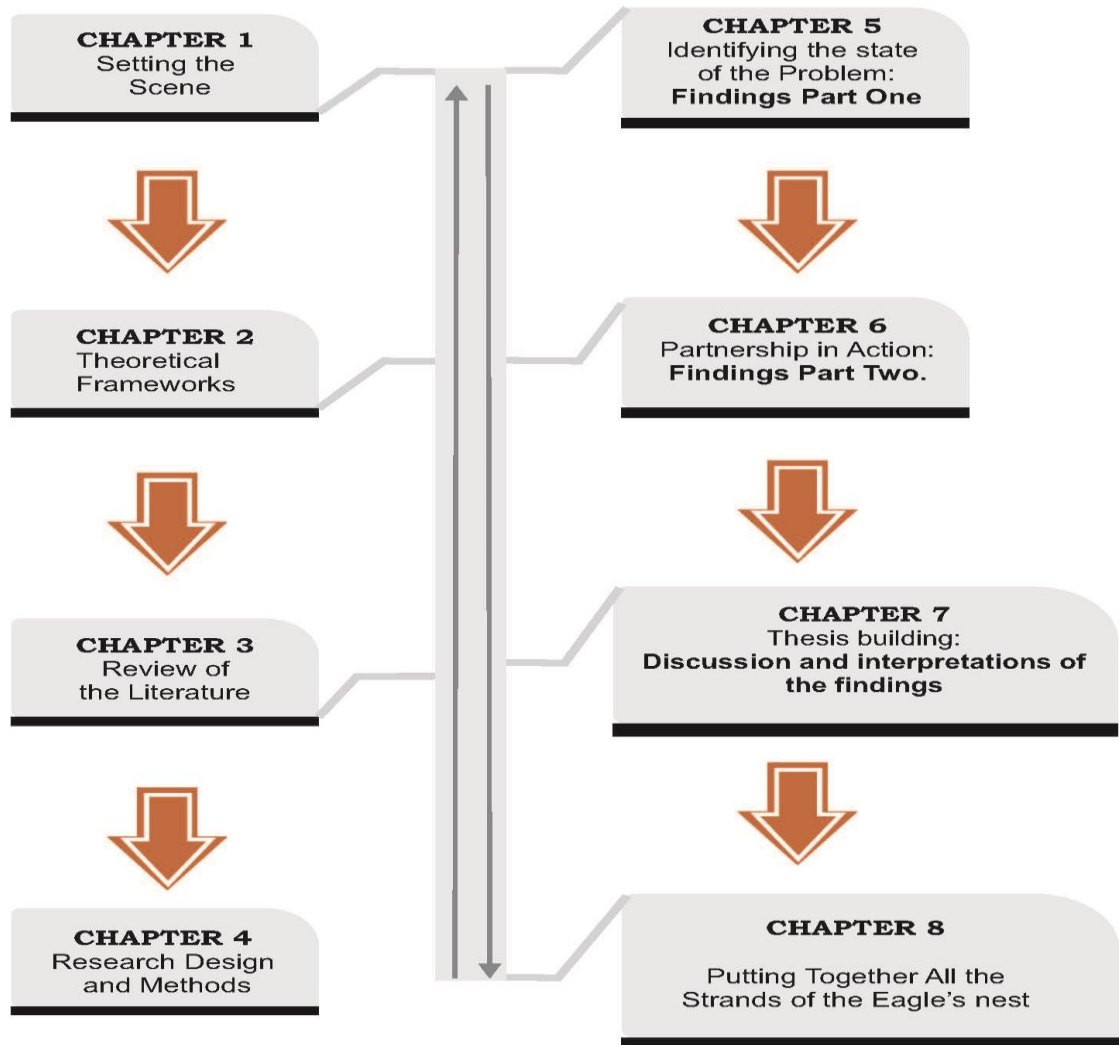


Figure 0-1: Structure of the study.

CHAPTER TWO:

THEORETICAL FRAMEWORKS

2.0 Overview

In each research study, it is important to identify a theoretical framework that gives research credibility and guides a researcher's thinking, beliefs and assumptions about oneself and society (Adom et al., 2018). Additionally, a theoretical framework assists a researcher to formulate the research problem, investigate the phenomena, develop an inquisitive mind, and attach meaning to the data collected (Guba & Lincoln, 1994). Therefore, a theoretical framework is 'the application of a theory, or a set of concepts drawn from the same theory to explain an event or shed some light on a phenomenon or research problem' (Imenda, 2014, p. 189).

Chapter 2 discusses the two selected theoretical frameworks-The Critical-emancipatory theory (CET) and the Bioecological systems theory (BEST). The Chapter further discusses the evolution in thinking by both the medical and social models which bring us to another discussion on the importance of social justice in service provision for people with disabilities and their families. Later, the chapter justifies the selection of two theoretical frameworks of the Bioecological System Theory and the Critical-emancipatory Theories and how they are linked to PAR. The chapter ends with a summary.

2.1 Medical Models

The origin of the medical model can be tracked back to the 19th Century when the role of health professionals and the use of modern medicine began to be enhanced. The medical model replaced the moral and/or religious model after the increase of scientific studies (Retief & Letsosa, 2018). The medical model also known as the 'clinical-pathological,' 'deficit model' or the 'individual model', is one of the models still being used by many clinicians to treat persons with disabilities (Oliver, 1990). The early assumption of the medical model was to view disability as a medical problem that resides in the individual who was expected to benefit from medical professionals (Retief & Letsosa, 2018). To Medical model proponents, disability has nothing to do with either social or geographical environmental barriers. The Medical advocates believed that a person with a disability is 'disabled by their impairment' which is independent of their social conditions (Barnes & Mercer, 1996). The main focus of intervention by the medical model is to 'cure, ameliorate the physical condition of the person to the greatest extent possible, and rehabilitation'(Retief & Letsosa, 2018, p. 3). Thus, disability was seen to be a physical defect, a biomedical problem and a dysfunctional abnormality that an individual has and must be cured or

treated (Barnes, 1999, 2001; Mulvany, 2000; Oliver, 1990). This approach disempowered parents as they could not make any decisions on the treatment protocol.

Literature has shown that the medical model inhibited the flow of critical information between the parents as primary caregivers and health professionals and in meeting cultural needs of certain communities (Franz et al., 2018; Harrison et al., 2014). This meant that clinicians could treat a disability condition based on “book knowledge” rather than a combination of parents’ experiences and their professional medical theories. In biomedical schools, issues of disability experience and its curriculum were often ignored as many Zambian medical students were not aware of disabilities such as ASD (Chansa-Kabali et al., 2019; Nyoni & Serpell, 2012). The poor flow of information between parents and professionals results in children with ASD been undiagnosed or not diagnosed (Nyoni, 2011).

The Medical model advocates concentrated in labelling a child with a disability as part of their diagnosis. The labelling and categorising of a person with a disability such as ASD has ignited society to view persons with disabilities with sympathy, discrimination and created a fertile ground for society to ignore parents and their children with a disability, hence excluding them from community participation (Watermeyer, 2013). Many persons with disabilities are denied an opportunity to get involved in policy decision making programs (United Nations General Assembly., 2017). This has influenced legislators in countries like Zambia who may have limited knowledge about disabilities to develop policy documents such as the Disability Act of 2012 and the Mental Health Act (2019) (GRZ,2019) that falls short of acknowledging the role of parents, in that there is no role or position assigned for a parent of a child with a disability in the executive boards. The Disability Act of 2012 and the Mental Act of 2019, on the position of the executive board, overlooks the responsibility parents play in the provision of services to children with ASD in Zambia. In addition, the two policy documents have no work policy frameworks on how and who should implement and take effective action. Such gaps have led many organisations not to affect the policy as it is enforced by individuals who have a passion in disability matters rather than following the policy directive. For example, the two policy documents do not provide punitive punishment measures or laws that hold accountable individuals or institutions that disregard the right of persons with disabilities in their organisations.

These policy documents add to already existing legislation that has failed to meet the aspirations of parents of children with disabilities and their children with disabilities. This is because the policy documents are either too ambitious as compared to available resources (Ndhlovu et al.,

2016) or some stakeholders have limited knowledge on how to interpret them (Malungo et al., 2018). Such policy documents are examples of copy and paste documents from the Global North that are enacted by the government without looking at the budget implications and levels of education of the majority Zambians mostly younger mothers. The policy documents are hardly translated in local languages to meet the needs of the illiterate community. It seemed the documents were only meant for the educated and the academicians to use them for research purposes.

Therefore, the medical model disempowered families of children with ASD by preventing parents and children from actively making decisions on matters of economic resources, education and health that were aimed at improving their health and well-being.

The medical model was more beneficial to physicians than to the person with a disability, who required a voice to express their challenges rather than professionals making decisions on their behalf (Barnes, 1999). In addition, the medical model seemed to promote the wheel of social injustices in the Zambian communities that had limited resources, and this made the enlightened parents to question professionals on issues of ASD at an individual level. Consequently, this study advocated for the PAR approach.

2.2 Social model

To reverse the wheel of social injustice, disabled theorists developed a model called the social model. Unlike the medical model, the social model was created by the persons with disabilities themselves (Oliver, 1990). The social model was developed to remove barriers in the environment and enable people with disabilities to have the same opportunities to determine their own lifestyles. The disabled people in the USA and United Kingdom were some of the early advocates of the social model. In the 1970s, in the United Kingdom, people with disabilities formed the disability movement to advocate for social inclusion in their respective environments (Union of the Physically Impaired Against Segregation (UPIAS) 1976). The disability group had a political context during the campaign for social inclusion and this changed how disability was defined. Publications such as *Attitudes and Disabled People* by Vic Finkelstein (1980) and *The Politics of Disablement* (1990) by Mike Oliver have political content and both authors developed the definition of disability as a relationship between people with impairment and a disabling society. Disability was defined as:

All the things that impose restrictions on disabled people, ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable

transport systems, from segregated education to excluding work arrangements, and so on (Oliver, 1996, p. 33).

Social model theorists believed that disability is caused by the attitude of the society who fail to remove barriers in the environment. To support this claim, the social model distinguished between a disability and an impairment. The aim of distinguishing the two was to educate the community on what constituted an inherent personal challenge and an acquired environmental barrier. According to the social model, impairment was understood as having a 'defective limb, organ or mechanism of the body' (Oliver, 1992, p. 22) whilst disability is '... the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (Oliver, 1992, p. 22).

The distinction between the two concepts enhanced the belief by social model activists that, disabling of an individual is caused by the barriers created by society through inaccessible environments (Oliver, 1990). These barriers range from negative social attitudes, institutional discrimination, poor unusable transport systems, segregated education and working places (Oliver, 1990; Union of the Physically Impaired Against Segregation, & Alliance, 1979). The social model advocates believed that environmental barriers have continued contributing to the marginalisation of a person with disabilities by the community (Shakespeare, 2004; Watermeyer, 2013). Therefore, the social model aims at removing the barriers in the environment, enhancing the rights of citizenship for persons with disabilities, and advancing the enactment of anti-discrimination legislation (Shakespeare, 2004).

Like the medical model, the social model had its limitations. One of the limitations was that the proponents of the model were all adults who wanted to live an independent life without considering the welfare of children. For example, it does not consider the welfare of children with severe intellectual disabilities. Children with severe intellectual disabilities may still need the support of their parents or caregivers for survival (Karisa et al., 2021; McKenzie et al., 2014) even in adulthood. Secondly, the Social Model had successfully been implemented among persons with physical disabilities by improving the social structures. However, it did not consider the environment for children with neurology impairments on how best they can adapt to the social norms of the society (Woods, 2017).

The model neglected the role of parents and parent-led support groupings that may require skills on how to advocate for the social inclusion of their children. In addition, the social model failed to fight against the pressure exerted on children with ASD to adhere to neurotypical societal demands designed for the typically developed individuals (Woods, 2017), rather than society accepting the world of children with ASD. Thirdly, the social model is more concerned about emancipating an individual with a disability rather than promoting the interdependences emancipation of both the person with a disability and those without. It overlooks the fact that each parent is an expert on each child's ASD condition, and that ASD management differs from one parent to the other (Woods, 2017). Therefore, this study brings in another dimension where society must not put an umbrella demand for social change to the environment such as access to the road network, ramps on buildings for all persons with disabilities, but advocate for support services that meet each individual social need. Another gap in the social model, is that it does not take into consideration the social environment.

The limitations in the Medical and Social models resulted in the World Health Organisation integrating the two within the Bio Psycho-social models as exemplified in the World Health International Classification of Functioning (ICF) (World Health Organisation (WHO), 2007). ICF acknowledges that illness and health are caused by the interaction between biological, psychological, and social factors. Bio (physiological pathology), Psycho (thoughts, emotions and behaviours such as psychological distress, fear/avoidance beliefs, current coping methods and attribution) and Social (socio-economical, socio-environmental, and cultural factors such as work issues, family circumstances and benefits/economics) (World Health Organisation (WHO), 2007).

Despite WHO adopting the ICF, which integrated the medical and social models, assessment for children with ASD had received little attention. The inadequacies of the social and medical models in addressing the needs of families of children with ASD required us to reconsider what frameworks spoke to ASD families' specific needs that promoted social justice and human rights.

2.3 Disability studies in family support services, social justice, and Human rights

A family is a very important unit in the welfare of each child because the family members are the primary caregivers. It is for this reason that in 2012, the United Nations, Department of Economic and Social Affairs (UNDESA) acknowledged the critical role families play in society

(United Nations. Department of Economic and Social Affairs, 2012). The UN member states are urged to:

Ensure the participation of families from diverse sections of society in designing, monitoring and evaluating family-focused policies through appropriate mechanisms' (United Nations. Department of Economic and Social Affairs, 2012, p. 3).

Despite such an appeal by the United Nations and recognising that ASD had become a public health concern, few studies have considered the well-being of families of children with ASD (Cridland et al., 2014), from the global South. Most studies focused on a patient and not the caregiver (Karst & van Hecke, 2012). For centuries, social justice and enjoyment of individual human rights eluded persons with disabilities and their families because of stigmatisation and discrimination (WHO, 2011).

History, some sectors in Africa viewed persons with a disability as semi-human, and the cause of the disability was conceived as unnatural or acts of witchcraft (Kabzems & Chimedza, 2002). Families of children with disabilities were the first to be accused of 'sacrificing' their child for a reward of bumper harvests (Kabzems & Chimedza, 2002). However such accession by scholars like (Kabzems & Chimedza, 2002) are refuted by Afrocentric onto-epistemology who believed that children with disabilities were embraced by the society. These Afrocentric onto-epistemology Africans scholars observed that they are many proverbs that Africans used such as (bo-bopuo) among the Basotho to relate to God's creation (Sefotho, 2021). Sefotho (2021) further support his argument that, in Africa, persons with disabilities were treated as equal human beings since they were part of God's created human beings.

Equally in Zambia, they are also many proverbs that consider all persons as equals. These proverbs require that each child, including children with disabilities need protection as they are considered as future leaders. Proverbs like *Imiti ikula empanga* (trees that grow are future forests) and *Ng'ombe Ni matole* (young calves are cows) show that a child is regarded as a future investment that is worth investing in.

However, other scholars still felt that many parents who had a child with a disability could not take pride in their child as they felt ashamed and embarrassed for having such a child (Kalabula, 2000). The local community could equally not see any value in investing in a person who had limitations and body impairments. However, this did not mean that people with disabilities were completely excluded from the community. Their social inclusion in the community was based on

their contributions made to the community (Groce, 2004) and both the community and parents mostly mothers treasured their children with disabilities (Sefotho, 2021).

In recent years and with the increase of human rights, the UN enacted the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which had increased the understanding of human rights and the rights for persons with disabilities and the value of a family, hence stating that we are:

Convinced that the family is the natural and fundamental group Unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with Disabilities (United Nations Rights of Persons with disabilities, 2006, p. x).

Despite the positive steps taken by the UN to popularise disability issues, social injustice continues to exist globally (World Health Organisation, 2011). The value of human inter-dependency as part of human civilisation and social development continues to be eroded. Kittay observed that:

human beings are naturally subject to periods of dependency, and people without disabilities are only “temporarily abled.” Instead of seeing assistance as a limitation, we consider it to be a resource at the basis of the vision of society that can account for inevitable dependency relationships between “unequal” ensuring a fulfilling life both for the carer and the cared for (Kittay, 2011, p. 49).

Mbiti once said:

Only in terms of other people does the individual become conscious of his being, his duties, his privileges, and his responsibilities towards himself and towards other people. When he suffers, he does not suffer alone but with the corporate group; when he rejoices, he rejoices not alone but with his kinsmen, his neighbours, and relatives whether dead or

alive... The individual can only say: “I am because we are; and since we are, therefore I am (Mbiti, 1969, p. 108).

As observed by Mbiti above, the human rights model of social and medial models is seen as a relationship that is not collaborative in nature between the parents and professionals. This is supported and more associated with an African Chichewa proverbs which state that “*Chibwenzi cha nkwangwa pokwela mu mtengo*’ (the relationship that exists between an axe and a person when climbing a tree). The Human rights models only appreciate parents as caregivers without considering their own challenges as they raise a child with a disability. Parents of children with disabilities are only most appreciated when they manage to empower a child with a disability and later are ignored by both a person with a disability and service providers, hence the meaning of the Chichewa proverbs above.

Parents play a critical role in the child’s early stages of life and some even in adult life. Parents’ voices can reveal more information about the history of how a child became disabled, (Kittay, 2011). Kittay calls it morally unethical to emphasise autonomous individuals and not inter-dependency:

I want to suggest that ethics that puts the autonomous individual at the forefront, that eclipses the importance of our dependence on one another, and that makes reciprocal exchanges between equals, rather than the attention to other’s needs, the model of ethical interaction is not one to be preferred in the construction of ethics of inclusion—at least not without the correction of an ethic of care (Kittay, 2011, p. 51).

Therefore, the inter-dependence between parents and persons with disabilities in seeking support services is part of social justice. My argument is that social justice and equal enjoyment of human rights must apply to all people at all levels of life. This includes ASD parents as caregivers of children with disabilities. We live in one global village where we depend on each other. Therefore, the role of parents as primary caregivers play to persons with disabilities cannot be ignored.

It is for this reason that this thesis applied the Critical-emancipatory Theory and the Bio-ecological frameworks. These two theoretical frameworks included parents as key stakeholders in finding solutions to challenges affecting them and their children with ASD. In addition, the two theories highlight how parents viewed and experienced disabilities. Shakespeare observed that: ‘It is quite possible to have a disability rights perspective without a strong social model

approach' (Shakespeare, 2004, p. 10). Therefore, for parents to have both skills and knowledge of disability rights and the value of social models, appropriate theoretical frameworks needed to be selected in the research studies. I needed theoretical frameworks that anchored on parents' full participation as key players in a child development. I now discuss how social justice can be achieved among oppressed groups through Critical-emancipatory theory and Bronfenbrenner's Bio-ecological systems theoretical frameworks.

2.4 Towards the selection of theoretical frameworks

In this section, I now explain the various selected frameworks from the transformative paradigm perspective. The selected frameworks considered knowledge as not neutral but as a means to improve society (Mertens, 1999). The two frameworks were appropriate in this study. Namely:

- i. The Critical-emancipatory theory (Habermas, 1984). The Critical-emancipatory theory was a social theory that aimed at critiquing and bringing social change to society as a whole and understand how the world worked. This theory was employed in this study to parents of children with ASD who had a practical intent to promote social justice in society. The theory aimed at emancipating people from rigid structures of dominations.
- ii. Bronfenbrenner's Bio-ecological systems theory (Bronfenbrenner, 1994) was a theory that explored an individual's connectedness to their environment and how the co-dependence between the individual and the environment is critical in human development. The two selected theoretical frameworks were appropriate for this study because they are consistent with the current global trend in the health sector, where there is a shift in service provision, from the professional-based approaches to family-centred interventional models (Tomlinson et al., 2014).

2.5 Critical-emancipatory Theory (CET): A Historical Emancipatory Perspective

The theory originated from the Frankfurt School, formed by Western Marxist social researchers from Frankfurt, Germany. The theory considered social justice and the relationship of knowledge, power, and ideology to be at the centre of human learning experiences (Habermas, 1971). Paulo Freire was an important exponent of this theory in education. He rejected the 'banking concept of education' (Freire, 1972) where the learner is viewed as a dehumanised object where power and knowledge are only invested in the hands of the teacher. Freire advocated for a humanising pedagogy where a permanent relationship of dialogue between the teacher and the learners is established (Freire, 1972).

Paulo Freire and colleagues were influenced by the work of Karl Marx who became discontented with capitalism theories to achieving human emancipation. Max Horkheimer popularised Critical theory in 1937 in his essay *Traditional and Critical theory* “(Horkheimer, 1972; Sherratt, 2010; Sollazzo, 2016). In his work, Horkheimer compared ‘traditional theory’ to ‘Critical theory. He contended that traditional theories separated the researcher from the participants. In contrast, the Critical-emancipatory theory empowers an individual (human emancipation) by liberating individuals from ‘mental slavery’ and any other forms of oppression and domination that occur when peoples’ destiny is determined and prescribed for them (Patton, 2002). Critical-emancipatory theorists are concerned with the felt needs and suffering of the actors (parents of children with ASD). Fay rightly attests that: ‘critical theory is rooted in the felt needs and sufferings of people, and therefore, the critical theorist must come to understand these actors from their own point of view’ (Fay, 1975, p. 94).

Literature shows that individual unmet needs were created by social structures and systems that had historically served to oppress certain groups of peoples in society (Kramer-roy, 2015), such as parents of children with ASD. These structures were intertwined and difficult to break because of the historical traditional rigidity to accepting new knowledge and social change. Borrowing Horkheimer’s (1995) words, ‘Critical theory is motivated today by ‘the effort to abolish the opposition between the individual’s purposefulness, spontaneity, and rationality, and those work-process relationships on which society is built’ (p. 210). Affected groups such as Zambian families of children with ASD must advocate for social justice, fairness, equitable distribution of resources and services regardless of geographic location, socio-economic status, and race, or gender of a child and parents with ASD in their community.

Parents must act on social injustice and remove or eradicate the discontent caused by contradicting social orders (Fay, 1975). These challenges could be eradicated when the parents understand how knowledge is generated that can bring social change in the community. Habermas, a contemporary theorist challenges individuals to understand how knowledge is generated and interpreted (Habermas, 1984). Habermas drew up three primary generic cognitive categories of knowledge called '*knowledge constitutive*'. These were:

Work knowledge: This is the knowledge an individual gained and used to manipulate the environment with empirical evidence. This type of knowledge was based on facts and proof. However, in this study, the goal in applying the Critical-emancipatory theory was not to prove a theory or a hypothesis, but to have a deeper insight into how participants use the working

knowledge. The goal was to observe the behaviour and actions and understand how multiple realities are socially constructed and interpreted by the participants themselves in their environments.

Emancipatory Knowledge: Under this domain, individuals gained knowledge to identified challenges and become critical of their environment. Knowledge was gained through self-emancipation which leads to transformation and a consciousness raised group. People could give a self-reflection about the challenges they faced. *This type of knowledge resonated with this study as discussed in Chapter 6.*

Practical Knowledge: This type of knowledge deals with human social interaction or '*communicative action*'. Habermas advanced the communication action approach to fighting injustices in modern capitalism, where few people control all the resources. He argued that to free society from the crisis of oppression and exploitation by the capitalists, people must learn to communicate, develop common plans and learn to be democratic (Habermas, 1984). For example, for parents of children with ASD to access the services, they must have the power to 'voice' out their grievances about their unmet needs and those of a child. Habermas (1984) called it "*communicative action*" or the "*ideal freedom of speech*". Marginalised Zambian parents of ASD children needed to express themselves, be heard, debate on issues of social, political, and public life that affect them daily. This means that society has to accept the content of the parent's messages rather than concentrate on the grammar aspect of what they present (Habermas, 1984). In this study, parents needed to communicate their actions in the familiar local language appropriate to them. These Zambian parents of children with ASD needed capacity knowledge and skills on how to "expose (s) forces that affect their lives. Critical theory provides an opportunity for parents to express their feelings as, 'every individual is granted dignity regardless of his or her location in the web of reality'(Steinberg & Kincheloe, 2010, p. 140). The dignity bestowed on each individual, enabled parents to fight against injustices, bias, and abuse of power and confront the social injustice in the society (Kincheloe, McLaren, & Steinberg, 2010). Steinberg and friends state that any 'continuation of human suffering by conscious human decision is morally unacceptable behaviour that must be analysed, interpreted and changed (Steinberg & Kincheloe, 2010, p. 140). This type of knowledge is like what is observed in Chapter 5.

In this study, I linked some of the Habermas cognitive knowledge to emancipatory disability research because it resonated well with the current study as discussed below.

2.6 Emancipatory Disability Research (EDR)

The EDR originated from the community of persons with disabilities who felt a violation of their rights by non-disabled researchers who could not involve them in research that affected them (Oliver, 1992). Gaps were observed in how traditional research dealt with the issue of disabilities (Barnes, 2001, 2003; Oliver, 1990). The disability activists felt that the emancipatory disability research (EDR) should aim at exposing social inequalities among the oppressed group and bring social change in the community (Henn et al., 2006). Barnes (2001) contended that the EDR agenda warranted the transformation of the material and social relations of research production. He argued that disabled people and their organisations should have control over the research process, funding and the research agenda (Barnes, 2001). Furthermore, it was argued that non-disabled researchers conducting research on behalf of the people with disabilities need to co-work with disabled people organisations (DPOs). The DPOs are the ones to set the agenda, determine how the results should be disseminated, accessed and empower them to understand their oppression (Barnes, 2003). Therefore, EDR aimed at the demystification of existing structures that created barriers in the environment for persons with disabilities. It called on non-disabled researchers and persons with disabilities to be co-researchers in the research study (Barnes, 1992).

This thesis took a similar approach by allowing participants to be directly involved in the study. A search of the literature in Zambia showed that there was limited information on studies that had employed EDR to understand the experiences of Zambian families of children with ASD in accessing support services. In this study, I realised that emancipatory disability research could not be understood in isolation without linking it to PAR since both EDR and PAR are intertwined and are tools that participants could use to empower themselves and others.

2.7 Linking Emancipatory Disability Research (EDR) to PAR

This section highlights how the PAR methodology resonated well with the Critical-emancipatory theoretical framework. PAR and Critical-emancipatory theory focuses on; empowering the marginalised people, advocating for social justice (McNiiff & Whitehead, 2006), promoting dialogue and group team building (Kemmis & McTaggart, 2007; McNiff & Whitehead, 2010). It is through EDR and PAR that parents are ‘conscious raised’ that fighting

traditional historical oppressors is not a simple battle, as it is about power imbalances and finding solutions on how to address them (Kramer-Roy, 2007; Swartz & Nyamnjoh, 2018).

The EDR and PAR are interwoven as both approaches aim at promoting participation and transformation of affected individuals and communities. It was through PAR and EDR that I was enabled to converse in a dialogue with the oppressed and analyse their actions and behaviours, both in and outside the field. I agreed with Kramer-Roy who stated:

There is a very close ‘fit’ between these two approaches, with the only obvious differences being (1) that participatory action research has been used by a wide range of people facing marginalisation for different reasons besides disability and (2) that participatory action research tends to use a cyclical process of action and reflection, whilst in emancipatory disability research, multiple methods are used. There are no evident contradicting principles between the two approaches and provided the researcher has a genuine commitment to achieving the emancipatory goals and can work reflectively, a participatory action research study involving disabled people should meet the criteria of emancipatory disability research (Kramer-roy, 2009, p. 95).

It is evident from a study by Kramer-Roy above that PAR and EDR allow researchers to ‘put their knowledge and skills at the disposal of disabled people’(Barnes, 1992, p. 122). People with a disability became co-learners and owned the project, resulting in promoting accountability during the research process and helping non- disabled researchers to develop policies that took into account the interest of the affected group (Barnes, 2001). Such an approach empowered participants to develop critical thinking and be consciously raised on phenomena affecting them as discussed below.

2.8 Linking PAR to Critical-emancipatory theory

This thesis was not only about generating new scientific knowledge about parents’ experiences with ASD, but also exploring the benefits of participatory action research (PAR). Like PAR, Critical-emancipatory theory is an appropriate theoretical framework for this thesis because of its applicability to qualitative research. The framework energised parents to act on the phenomena affecting them as observed also in the PAR approach. The framework further allows individuals to develop a critical process of reflection that emancipates them from taking a neutral position of falsehood and ignite in them the desire to challenge the oppressive regime.

The core focus of the critical theory was social justice among marginalised whilst the framework took an emancipatory approach to disability research that is aimed at empowering persons with disabilities. Freire (1968) elaborates that the empowerment of the marginalised group is achieved when the researcher and the researched collaborate. The collaboration must be practiced in local environment and must be culturally contextualised as individuals are critically emancipated with knowledge and skills on how to bring social change in the community. The theory selected and appropriate for this study was the Bio-ecological systems theory as discussed below.

2.9 The Bronfenbrenner Bio-Ecological Systems Theory (BEST)

The Bio-ecological model was developed by Bronfenbrenner in the 1970s (Bronfenbrenner, 1994) to consider the social interconnectedness between the individual and their environment (Bronfenbrenner, 1994). This theory arose against the growing interests among researchers and mental health professionals who wanted to understand the relationship between an individual's functioning and their environment (Suarez-Balcazar et al., 2014). Bronfenbrenner postulated that activities in the environment impact human actions and behaviours and he believed that any disconnection between the two can negatively impact human development (Bronfenbrenner, 2005; Rosa & Tudge, 2013).

The key prepositions in Bronfenbrenner's (1994) theory were: (a) human development is a continuous process through a life span that is influenced by activities in an individual's local environment, (b) the nature and style of these interactions are dependent on the personality (biological components unique to the developing individual) the type of the players, the stimulus in the environment, and the developmental effects being examined (c) the existing reciprocal relationship between an individual and the environment are affected by historical accounts of events and, time (d) each individual's behaviours and actions are determined by many factors within the environment (e) human development was based on the interdependence between an individual and the environment and both impact each other (Etteka & Mahoney, 2017).

It is critical to understand what Bronfenbrenner considered to be human development. To him, it was "the phenomenon of continuity and change in the biopsychological characteristics of human beings, both as individuals and as groups ... [which] extends over the life course, across successive generations, and through historical time, both past and future" (Bronfenbrenner & Morris, 2006, p.793).

However, Bronfenbrenner himself kept on improving the theory because he recognised that human development is a continuous process. It was for this reason that from the 70s to 2000, the

theory underwent evolution. According to Rosa and Tudge, (2013), the theory was divided into three phases. Phases 1,2 and 3.

In Phase 1 (1973–1979), Bronfenbrenner focused on the contribution of an individual to his or her environment and various ecological that affect an individual as an organism. This is in his studies which culminated in the publication of *The Ecology of Human Development* (1979).

In Phase 2 (1980–1993), Bronfenbrenner modified the theory and considered the role of an individual in the human developmental process. Bronfenbrenner included culture at macrosystem levels and the significance of chronosystem in human development (Rosa & Tudge, 2013). He argued that human development changes at a function of time because of environmental changes in the community.

In Phase 3 (1993–2006), Bronfenbrenner included the proximal processes in human development. This was the birth of the Bio-Ecological Theory, which considered the importance of human traits in proximal processes (Rosa & Tudge, 2013). Bronfenbrenner hypothesised that human development was a joint product of the Process-Person- Context-Time (PPCT) model (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). The product of a person referred to the individual attributes such as age, gender, and competencies as an individual socialises with the environmental setting to influence development. The process factor is the complex interdependence between an active individual with the immediate local environment (proximal processes) (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). The person factors represented the roles and contributions that an individual played in the environment while the context-time factors were the five systems levels of micro, meso, exo, macro, and chrono systems.

It is against this background that Bronfenbrenner ecological theory framework was selected for this thesis. This is because of its interconnectedness that creates critical social thinking and empowers parents as an affected group to find a ‘voice’ in their environment at all the five Bioecological systems, starting with microsystems, mesosystems, exo systems, macro and chronosystems levels.

Secondly, Bronfenbrenner ecological theory has two main propositions in which the theory was anchored and that speaks to this current study. The first one is the claim that reciprocity exists between the developing person and the environment, and this relationship can become more advanced and complex over time as an individual grows and the environment evolves. The

second proposition is that the effectiveness of proximal processes can be influenced by many factors such as an individuals' behaviours and actions and the local environment (Bronfenbrenner & Morris, 2006). The two propositions have had an impact on human development. It was important in this study to understand how the two propositions influenced the lived experiences of parents of children with ASD from the Zambian context. In addition, I wanted to understand the type of 'processes' that would enhance an individuals' growth and development. Through this study, I wanted to understand how the concept of 'proximal processes' and the multiple ways an individual learns.

Bronfenbrenner coined the term 'proximal processes' as he was concerned with activities that a person is involved in during the interaction, the learning period and development (Bronfenbrenner & Morris, 2006). He observed that learning and development are dependent on the individual's effort, time allocated to undertake the activity and the context (Grace et al., 2013). During his research, Bronfenbrenner further identified three individuals' characteristics on how a person interacts with others. The three characteristics identified were demand, resource, and force characteristics (Tudge et al., 2009).

Demand characteristics: These were based on an individual's interaction and expectations from the community. Every person may develop the first impression of an object during the first interaction with an individual and the environment. This first impression might include an individual's physical appearance, skin, and gender (Tudge et al., 2009). The perception that an individual hold can influence the type of support a person would access. It was important in this study to understand how 'demand characteristic' had an impact among Zambian families when accessing ASD support services. It is for this reason that the concept of demand characteristic was equally applied in this study as discussed in Chapter 6 where parents formed a parent-led support group.

Resource characteristics: Bronfenbrenner looked at an individuals' resources such as mental intelligence, social-emotional and access to material resources that assisted a person to survive in the environment (Tudge et al., 2009). In the current study, I wanted to find out whether parents had such resources as discussed above by Tudge et al., (2009) and they required resources to have a quality life.

Force characteristics: Tudge and colleagues observed that force characteristics were about a change of mindset by an individual. They looked at a developmental pathway of an individual

having either a positive or negative direction. People with positive minds tended to be more motivated, persistent and were determined to undertake a task; unlike those with negative force characteristics who lacked motivation, seemed not to be interested in issues affecting them and had to be pushed to do an activity (Tudge et al., 2009).

The three related characteristics of demand, resources and forces were like what Zambian families advocated for as discussed in Chapters Five and Six (See Chapters 5 and 6) and how I linked the theory to the current research.

2.10 The Bio-ecological Systems Theory (BEST) and Research

In this section, I now discuss how the Bio-ecological system framework was applied to the Zambia setting in this study. The Bio-ecological framework had the potential to be applied in the Zambian cultural settings because it has been used in other settings in Africa and proved to be appropriate. For example, Ufoshu (2017) used Bronfenbrenner's ecological model to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria. Predescu and Darjan (2018) employed the model to establish good practices and interventions that were beneficial to parents of children with ASD, professionals who worked with children with ASD, and the general community. This was evident to prove that the Bio-ecological systems theory model had greatly been used in disability studies (Stephens, 2018; Atilola, 2014). The results had been successful. The model has been used to develop advocacy skills among parents to see the urgent need of accessing early intervention services (Predescu & Darjan, 2018). The Bio-Ecological Systems Theory resonated well with this study because of the link to the PAR approach whose benefits are discussed below.

2.11 The link between the theoretical frameworks and the PAR approach

There was a link between Bronfenbrenner's Bio-Ecological Systems framework and the PAR approach. This was supported by Rose and Tudge who observed that the:

Bio-Ecological theory in its current or mature form specifies that researchers should study the settings in which a developing individual spends time and the relations with others in the same settings, the personal characteristics of the individual (and those with whom he or she typically interacts), both development over time and the historical time in which these individuals live, and the mechanisms that drive development (proximal processes) (Rosa & Tudge, 2013a, p. 244).

The use of the PAR approach from an ecological perspective assisted me to understand whether parents could perform effectively when raising their children within their local environment or on their own or they needed support from the environment. Through PAR, the parents could evaluate their capacity to function well, understand how external factors such as flexibility of job schedules, adequacy of childcare arrangements, the presence of friends and neighbours, quality of health and safe neighbourhood could have an impact on how the current ASD services in Zambia were perceived.

Linking the Bio-Ecological Systems framework to the PAR approach abled me to understand how parents are influenced by many factors when seeking to access support services. It was through PAR that I was able to understand how local environment (internal) and other ecologies (external) an individual interacts with indirectly affect the person's perception of the phenomena (Grace et al., 2013). Parents used PAR methodology as they engaged in different activities in their respective communities in all the five Bronfenbrenner sysstem levels during the action cycles as discussed in chapter 5 and 6.

Bio-ecological framework resonated well with this thesis because the ecological model shaped human development at the local level so that . . . 'those that may already be operating today to influence what human beings may become tomorrow' (Bronfenbrenner & Evans, 2000, p. 117) were emancipated and capacity built with knowledge and skills on how to advocate for support services.

It was through the Bio-ecological system theory that participants realised that the environment consisted of interlinking systems that create a reciprocal relationship at micro-, meso-, exo-, macro and chrono systems (Bronfenbrenner, 1979) levels during the human development process.

2.12 Summary of the Chapter

The selected theoretical frameworks set a tone for my journey to discover and address the nature of oppression that existed in service delivery for parents of children with autism in Zambia. The selected theories created a dialogue space for parents to interact with key stakeholders who still design and implement policies that marginalises some sections of the society.

The Critical-emancipatory theory is rooted in the felt needs and sufferings of people and that the community needs to understand the affected parents of children with ASD point of view. The Critical-emancipatory theory promotes critical thinking among the marginalised groups. This

ignites the affected parents of children with ASD to find means of confronting the oppressive regime systems. Through Critical-emancipatory theory, parents are required to learn to understand the dynamism of social, political, and economic changes that occurred in the environment. These parents need to quickly adapt to the changes in the environment and address them quickly before they burden them and affect their health and well-being.

The Bio-ecological framework was appropriate and applicable to this study because it provided tools to empower families of children with autism so that they could transcend the burdens placed on them by society. The problems emerge as individuals interact with the local environment over time. The existing reciprocal relationship between an individual and the environment is affected by historical accounts of events and time. All such relationships that exist between the parents and the environment are experienced by an individual at all the five system levels and were applied in this study.

As discussed earlier, this relationship existed at the micro-level, which was applied to show the role of neighbours, teachers, and other community members in supporting of families of children with ASD. At mesosystems, it was applied to understand the connection between the microsystem's actors in the environment, such as teachers both in the mainstream and special schools and families of children with ASD.

At the macro level, the model looked at the influence and the role which special teachers, health professionals, and social workers had and played on service delivery. At the ecosystem, it was applied to understand the relationship between parents and stakeholders and the influence of culture in accessing services.

The Chrono level recognised how the environment and parents' perceptions and attitudes changes over time, mostly when the affected group is emancipated.

The next chapter discusses the literature review and how the two frameworks were applied in other reviewed literature.

CHAPTER THREE:

LITERATURE REVIEW

Reviewing of the literature is essential, not only in providing a context for the research subject and specifically limiting and identifying the research problem, but also in providing you with important information for subsequent parts of the research investigations, such as alternative theoretical standpoints and suitable research methods (Walliman, 2011, p. 137).

3.0 Overview

One of the key tasks a researcher undertakes when writing a thesis is to review the literature related to the research problem. Reviewing the literature is important as stated in the above quote by Walliman. A researcher must know about the research topic under discussion, develop a theoretical framework, justify the selected research design and methodology and develop research questions that address gaps in knowledge (Cresswell, 2014). In addition, the review of the literature “ought to follow a systematic, meticulously designed process, characterised by perceptive reading and attention to detail, particularly that which relates to your research problem” (Walliman, 2011, p. 136).

To search for literature, different strategies were used. This included an exhaustive search for literature from the University of Cape Town library, Google Scholar, and the Government of the Republic of Zambia. Ministries’ libraries and documentary centres. The articles selected were mostly peer-reviewed and chosen based on their relevance to the study. These articles were from several databases, including Premier; Africa-Wide Information; African Index Medicus; Eric (Education database); CINAHL (Cumulative Index of Nursing and Allied Health); EBSCO Databases, PsycArticles, and PsycInfo; EBSCO Host; Pub Med; Pro-Quest, Medline, and the UCT open Google scholar. Other sources of literature were from the use of books from the University of Cape Town and the University of Zambia libraries.

Chapter three will review the current literature on the understanding of ASD as a neuro-developmental disorder, ASD aetiology, its global prevalence rate, epidemiology, and the history of diagnostic criteria. The literature search extended to how parents understood ASD from the medical, African traditional healing, and religious perspectives. Additionally, the chapter will further review the literature that looked at the burdens that parents experienced in accessing ASD services, social support services, and the value of parents forming a parent-led support group.

3.1 Understanding ASD as a neuro-developmental disorder

This section explains how ASD is globally defined. It will also highlight the global, Africa and Zambian ASD prevalence rates. Later, the chapter discusses the evolution of ASD diagnosis from a historical perspective and the levels of ASD awareness amongst Zambians.

3.2 What is autism spectrum disorder (ASD)?

ASD is a life-long heterogeneous group of neurodevelopmental conditions marked by three core deficits: impaired communication, impaired reciprocal social interaction and restricted, repetitive and stereotyped patterns of behaviours or interests (American Psychiatric Association, (APA) 2013; Brondino et al., 2015). According to the DSM-5 manual, autism is a spectrum because the manifestation of the impairments varies in range and levels of severity and intensity and it affects the child's acquisition of other developmental skills differently (American Psychiatric Association, 2013).

The causes of ASD remains unclear (Ennis-Cole et al., 2013; Faras et al., 2010; Levy & Hyman, 2015). However, it has been linked to many factors such as genetics (Herbert & Koulouglioti, 2010; Levy & Hyman, 2015). One of the genetic conditions is the Fragile X Syndrome (Armatas, 2009), a genetic condition disorder that is characterised by mild-to-moderate intellectual disability.

Other studies have linked ASD to environmental factors such as non-optimal breastfeeding practices, high levels of Vitamin D deficiency, and increased exposure to pollution, pesticides and heavy metals (Virolainen et al., 2020). Other environmental causes are equally linked to endocrine disruption and mental stress (Cheroni et al., 2020; Kubota & Mochizuki, 2016). Neurotoxicologists have observed that chemicals also contributes to the cause of ASD (Cheroni et al., 2020). Therefore, both environmental and genetic factors are involved in the cause of ASD (Kubota & Mochizuki, 2016).

Research from high income nations suggest that autism is under very strong genetic influence, and it is not only linked to a single gene disorder such as X, but also to common gene variations. These genes in children can be inherited from the parents (Bai, et al., 2019; DeThorne & Ceman, 2018; da Costa et al., 2022). However, in Low Income Countries, like Zambia, there is limited knowledge and understanding about the aetiology of autism from a scientific perspective (Chansa-Kabali et al., 2019; Macha et al., 2020; Nyoni, 2011; Nyoni & Serpell, 2012; Washington-Nortey & Serpell, 2021; Wonani & Muzata, 2019). It may very well be that environmental factor such infectious diseases, malnutrition, water and air pollution, chemical

metals from mines and large industries play a much more substantial role in these settings. However, there are limited publications in Zambia that associate the causes of ASD to the above factors.

Globally, presently, there is no one universal cause of ASD, and globally there is no cure for ASD (American Psychiatric Association, 2013; Vivanti et al., 2014). International insights on treatment for ASD after DSM 5 recommended the use of Applied Behaviour Analysis (ABA) (Dixon et al., 2019; Lim & Draper, 2011) and Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) (Mazza et al., 2020; Turner-Brown et al., 2019). Another therapy treatment that might ameliorate ASD or ‘mask’ symptoms involve Behavioural Educational Intervention (BEI) (Appiah-Brempong et al., 2020). However, the use of ABA, TEACCH and other behavioural therapies interventions does not cure ASD despite previous claims.

3.3 The global prevalence rates of ASD

The number of ASD cases reported globally has been on the increase (Centers for Disease Control and Prevention., 2020; Wannenburg & van Niekerk, 2018). According to the World Health Organisation, one in every 160 persons worldwide is a person with ASD (WHO, 2013b). ASD affects more boys than girls with the ratio of 4:1. Though there is insufficient data on the number of people with ASD in Africa, ASD is on the increase (Ruparelia et al., 2016; Wannenburg & van Niekerk, 2018) with concerns of under-recording in these countries (Bakare et al., 2009, 2008; Bakare & Munir 2011; Bakare, Munir & Bello-Mojeed, 2014; Ruparelia et al., 2016; Smith, Malcolm-Smith, & de Vries, 2016). The insufficient data on the prevalence rate of ASD in Africa can be attributed to inadequate diagnosis, lack of adequate awareness (Einfeld et al., 2012; Franz, Chambers, Isenburg, & De Vries, 2017; Hastings, Robertson, & Yasamy, 2012; Zeglam & Maouna, 2012) and limited publications (De Vries, 2016).

According to the Zambia National Disability Survey of 2015, it is estimated that 11% of the adults aged over 18 years and 4% of the children aged between 2–17 years were persons with disabilities. Luapula and Copperbelt Provinces had the highest number of both children and adults with disabilities (Government of the Republic of Zambia, 2018). The World Health Organisation indicates that 15% of the Zambian population are persons with disabilities (World Health Organisation, 2011). The discrepancy in the prevalence rates of persons with disabilities between WHO and the Zambian government show gaps in the instruments and methodologies which are used to capture data. The disparity in figures has a policy implication for services and resources allocation to persons with disabilities and their families. Zambia has no official data

on the number of persons with ASD. However, the available scanty data is a survey which was conducted by Nkole (2017). The findings showed that the prevalence rate was around 1.4% out of the five hundred and sixty children she surveyed (Nkole, 2017). However, the results may be difficult to generalise because the sample used was very small and based on one hospital-University teaching hospital. A concerted effort is needed among African member states to carry out statistical studies on the number of persons with ASD in their respective countries.

3.4 The evolution of ASD diagnosis and treatment

The early conceptualisation of autism began around 1910 with Paul Eugen Bleuler, a Swiss psychiatrist, who used the term autism to describe childhood schizophrenic patients who had withdrawn symptoms (Greydanus & Toledo-Pereyra, 2012). In 1927, Eugene Minkowski described persons with ASD as a “trouble generator” of schizophrenia (Minkowski et al., 2001). Later, in 1943, Leo Kanner, an American psychiatrist, shifted the understanding of autism by associating autism with psychogenic conditions. Kanner described children who showed little interest in social interaction with others as early infantile autism. He attributed the limited social interaction exhibited by children to the poor parenting style of mothers (Kanner, 1943). Later, in 1944, an Austrian paediatrician, Hans Asperger, described children with higher functioning intellectual abilities as Asperger. In 1980, the DSM-III manual separated autism from schizophrenia, naming it infantile autism (Gernsbacher et al., 2005). Seven years later, in 1987, the manual was revised (DSM-III-R), and the term “infantile autism” was extended to “autism spectrum disorder” (American Psychiatric Association, 1987). Since 1987, the definition of ASD has continued to be revised to the current DSM-V.

In Africa, it was only in the late 1970s that studies about ASD emerged. This was through the publication of a paper entitled *Childhood Autism in Africa* by Dr Victor Lotter, a psychology professor from the University of Guelph in Ontario, Canada (Lotter, 1978). Lotter screened 1321 children with intellectual disabilities in the Sub-Saharan African countries of Ghana, Kenya, Nigeria, South Africa, Zambia, and Zimbabwe. Thirty children showed autistic behavioural tendencies and nine were confirmed as having ASD, a rate of 1 in 45 children. Later in 1980, Lotter published his second paper. The four significant findings were: (1) traces of ASD characteristics were found amongst African children; (2) more boys than girls had autism, mostly those with moderate to severe intellectual disabilities; (3) children with autistic characteristics were coming from affluent families; and (4) African children showed less stereotypical behaviour as compared to children from the Western World (Lotter, 1980).

In the last ten years, leading studies in Africa witnessed an increase in the number of publications on autism. The studies highlights various topics on ASD which include; barriers and hindrances to support services faced by the parents (Mthombeni & Nwoye, 2018; Nyoni & Serpell, 2012; Ramseur II et al., 2019; Schlebusch et al., 2016), insufficiently skilled professionals and lack of cultural friendly diagnosis and treatment (Davids et al., 2019; De Vries, 2016), ASD awareness and understanding (Chansa-Kabali et al., 2019; Gona et al., 2015; Ruparelia et al., 2016), diagnosis and treatment (Bölte et al., 2019) and insufficient ASD policies in African (Abubakar, Ssewanyana, de Vries, & Newton, 2016; De Vries, 2016). Despite all such achievements that Africa has gained, there is still insufficient literature about ASD in Africa as compared to Europe and Asia Equally, they are limited studies that have explored parents experiences with current formal and informal services as discussed below.

3.5. Parents' experiences with formal and informal ASD support services

This section discusses parents' experiences in accessing formal and informal services, burden of caring and raising a child with ASD at global level. The section further discusses the burdens parents in Southern Africa and Zambia experienced to access the support services. Later I will explain the ASD awareness levels in Zambia and link it to the current Zambian policy documents that are related to ASD service delivery.

3.5.1 Parents' experiences with formal and informal support services

Globally, parents required formal and informal support social services which vary from one family to the other, due to the spectrum nature of autism. The social support services required include access to emotional, instrumental, appraisal support (esteem support), and informational support (advice support) services which are beneficial to them (Houston & Dolan, 2008; Pinkerton & Dolan, 2007). Studies showed that access to social support services by parents reduces stressors from the environment (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016). Additionally, parents who received support services have better emotional relationships with their children as compared to those who do not (Boyd, 2002). It was unclear on whether the situation was the same in Zambia.

Reviewed literature identified and categorised family support needs as including access to coordinated services from professionals, quality information, community support, training skills, professional-parent collaboration, finances, and counselling (Bower Russa, Matthews, & Owen-DeSchryvery, 2015).

Studies conducted in lower- and middle-income nations showed that parents require a lot of support services for them to access quality services. For example, Some parents required support needs which included societal awareness, support from the government, employment, independent living, opportunities for inclusion, socialisation and community participation (Sandy, Kgole, & Mavundla, 2013; Wang & Michaels, 2010). However, this family support needs to be varied across contexts and dimensions, such as social-economic, cultural, and education (McKenzie, 2014). For example, the greatest needs for Chinese families were ASD awareness of the society, support from the government, employment, independent living, inclusion in socialisation, community participation, and demands for professional skill training programmes (Wang & Michaels, 2010). In South Africa, families of children with learning disabilities needed support in finances, coping with emotional and discrimination practices, and parent-professional partnerships (Sandy et al., 2013), while Zambian parents required counselling services from professionals who were sensitive to their concerns during the diagnosis period and helping fathers accept the child's condition to remove the fear of having another child with a similar condition (Nyoni & Serpell, 2012). Additionally, Zambian parents required support on how to access respite care (Nyoni & Serpell, 2012).

Respite care is critical to parents, mostly single mothers and working parents who needed time-off from the daily behavioural challenges that come with caring for a child with ASD. However, caregiving, and respite care activities were a burden in most Sub-Saharan nations, mostly for parents of children with intellectual disabilities. This is supported by McKenzie and McConkey (2016) who explored the views of families caring for an adult with intellectual disability in South Africa. The finding revealed that respite care was limited, and some of the children were under the custody of old grandparents as caregivers.

Another study was conducted in Kenya by Molebatsi, Ndeti, and Opondo (2017) who wanted to determine the correlation of the caregiver burden and adolescents with psychiatric morbidity. The findings from Kenya revealed that caregivers of children and adolescents with psychiatric morbidity suffered high levels of caregiver burden. This could be because of limited strategies that parents in African uses to access respite cares from the cultural context. This is different with developed nations. A good example is in the USA where different strategies are used to promote respite care services. Murphy and Verden (2013) advocated the use of undergraduate students as respite carers to support families of children with ASD in the community. In the study, Murphy and Verden (2013) used undergraduate university students as parents' relief respite caregivers. The study showed benefits to both families and students as it provided opportunities for

undergraduate prevocational training and experience as well as increased opportunities for parents/guardians to engage in other activities in their environment without involving their children. The use of students as respite care providers provides an opportunity for ASD services providers to tap into the available rich human resources found in universities and colleges in providing the much-needed respite care support to families (Murphy & Verden, 2013).

The methodology used by Murphy and Verden can be appropriate to nations like Zambia which has a limited number of ASD skilled professionals to provide respite care. Furthermore, implementing the respite care programme in Zambia will provide Zambian students with opportunities to view “parents/guardians as primary care individuals with needs that extend beyond school-based support for the individual with a disability and perhaps allow students to be considered as equal partners in the education of children” (Murphy & Verden, 2013, p. 24). It was evident that there was a limited publication on the role of Zambian parents in accessing formal support respite care from professionals and the community (Chansa-Kabali et al., 2019). More studies need to be explored in this field of study. There was a need for parents to form parent-led support groups in collaboration with professionals that would help in providing respite care and training of communities and students on how to provide respite care support services.

Apart from respite care, Zambian parents with ASD children required social support from the community and professionals. Studies conducted in Malawi (Kelly, Ghalaieny, & Devitt, 2012) and Iran (Samadi, McConkey, & Kelly, 2013) amongst families of children with disabilities who were provided with social support by professionals showed that parents who received social support with the support of professionals showed increased family confidence, a larger social network, and active family participation in designing and implementing programmes. Therefore, engaging undergraduate students, professionals, and other service providers in providing social support services should be viewed as potential resources for parents.

Reviewed literature showed that Zambian parents desired to belong to an informal social support group where they could acquire knowledge and skills on how to manage the atypical behaviours of children with autism (Wonani & Muzata, 2019). Parents further wanted support from family members and the community. The support is critical to caregivers as it helps parents reduce stress. Nkhosi and Menon (2015) observed that most mothers received support from their other children, husband, or nuclear family. In a case where support was not available, friends, neighbours and church members assisted materially and socially (Nkhosi & Menon, 2015). Singogo, Mweshi & Rhoda (2014) conducted a qualitative study on challenges experienced by mothers caring for

children with cerebral palsy in Zambia. The authors observed that mothers of children with cerebral palsy lived isolated lives because of a lack of support from family, community members, and health care providers. Similarly parents of children with ASD in Zambia lived isolated lives of the community associating ASD with spiritualism and witchcraft (Nyoni & Serpell, 2012).

It was evident that parents of children with disabilities required psychological and social support to help them reduce stress and adopt coping strategies (Pepperell et al., 2018). Pepperell and others (2018) conducted a qualitative study among 19 parents to explore the psychological and social needs of parents within the same family unit in raising a child with autism spectrum disorder (ASD), the result showed that both genders suffered stress but adopted different strategies to deal with challenges. The strategies used to deal with challenges include problem-focused coping strategies, engaging in 'me time' activities, and disengaging from a stressor. The authors further revealed that more mothers reported engaging in emotion-focused strategies and accessing social support for emotional and practical support (Pepperell et al., 2018). To reduce further psychological stress, parents, specifically, traditionally cultured mothers, required support on how to make decisions on issues of health care and finances without first consulting men as breadwinners (Chirwa, 2017). This approach to family matters, as observed by Chirwa, might impede a child to access early intervention services because, when the father refused to provide money for health care, that significantly affected the health and well-being of the child. The above literature cited in this section is in line with the ecological model, which highlighted the interconnection between the parents and their immediate environment (Algood, Harris, & Hong, 2013; Bronfenbrenner, 1994).

To make available support needs, there was a need for a parent-professional collaborative approach to be employed. A parent-professional collaboration would help both parents and professionals to treat each other as equal partners in searching for support services. In this regard, parents should be viewed as co-learners, co-researchers, and core providers of knowledge and information about the condition of a child. This type of relationship can lead into building trust between the two groups. Scientific studies indicated that parent-professional collaborations resulted in low levels of observed stress, increased confidence amongst families (Blair et al., 2011), and improved service delivery (Murray et al., 2011).

The studies above support the importance of investing into informal and formal support services. Formal and informal support services can assist parents reduce the burden of caring and raising

a child with ASD. Globally they are many burdens that parents of children with ASD experience in caring and raising a child with ASD, as discussed below:

3.5.2 Burdens of caring and raising a child with ASD: International perspective

Families are a critical unit in shaping a child's personality development (Schofield, Conger, Donnellan, Jochem, & Conger, 2013), especially a child with a disability (Tint & Weiss, 2015). Parents are the providers of material, social, emotional, and physical support to a child with a disability. However, this role is more burdensome to many families of children with disabilities (Harper, Dyches, Harper, Roper, & South, 2013; Smith & Anderson, 2013) and the burdens experienced by parents are greater, compared to parents with typically developing children and those with other disabilities (Ludlow, Skelly, & Rohleder, 2012; Harper, Dyches, Harper, Roper, & South, 2013; Smith & Anderson, 2013; Tint & Weiss, 2015). These families face specific stressful challenges in raising a child with ASD (Boshoff et al., 2018; Dababnah & Parish, 2013; Mcconkey & Samadi, 2013; Nyoni & Serpell, 2012; Turnbull et al., 2006).

Similarly, parents of children with ASD experienced higher stress levels than parents of a child with Down Syndrome (DS) (Dabrowska & Pisula, 2010) and Developmental Delays (DD) (Estes et al., 2009). The stress among ASD parents emanates from couples spending less time together as compared with those without autism (Hartley et al., 2017). This is because the group of ASD parents is one of the most discriminated and marginalised by the society (Dababnah & Parish, 2013; World Health Organisation (WHO), 2013b). In addition, they have lower numbers of caregivers' support groups in the communities (Abubakar, Ssewanyana, & Newton, 2016; de Vries, 2016), limited home-based care coaching training (Guler et al., 2019); insufficient mental health experts (Davids et al., 2019; de Vries, 2016), and lack of ASD awareness (Gona et al., 2015).

Other schools of thought recommended the use of foster homes as one way to reduce stress (Seltzer et al., 2001). However, the use of foster homes may not be much applicable as it is a strange concept in Africa, mostly among families in the Zambian communities. Zambian families are a communal and collectivist society that believes in living together in one community and under one roof. Evidence also shows that very few persons with intellectual disabilities in Sub-Saharan Africa live in foster homes or residential facilities, as the majority live with their families (McKenzie, McConkey, & Adnams, 2014). Since ASD is hardly known in the community and it may not be known how best to assist families of children with ASD, this may result in families having the sole responsibility of taking care of persons with disabilities. This contributes to high

levels of psychological distress and health problems in parents (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016).

A systematic review of scientific literature on the challenges faced by families living with and caring for children with ASD in Brazil showed that parental emotional overload was one of the main challenges faced by mothers (Gomes et al., 2015). Additional causes of stress were the postponement of services, poor access to health services, and social support (Gomes et al., 2015). However, parents used different strategies to cope with stress, which included information exchange between affected families and an integrated healthcare network for patient and family support (Gomes et al., 2015).

It is not clear on whether parents of ASD children in Southern African experienced similar challenges as discussed above. I now discuss how parents experienced ASD in Southern Africa.

3.5.3. Parents' experience with ASD in Southern African region

The United Nations Sub-region of Southern Africa consists of nine countries. The countries are in the Southernmost part of the continent of Africa. The countries are Angola, Botswana, Lesotho, Mozambique, Namibia, South Africa, Swaziland, Zambia, Zimbabwe. This Sub-region is not exempted from health conditions such as ASD. Therefore, it is important for parents, professionals, and community members to have an insight about the cause, diagnosis, and treatment of ASD. Professionals need to consider the cultural activities in this sub-region which are similar in nature. This is because most of the countries were either colonised by the British or Portugal.

In this Sub region, there are limited studies on ASD. However, many studies about ASD condition have been conducted in South Africa (Franz, et al., 2017). There is evidence that parents of children with ASD in this region face challenges in accessing ASD support services (Chitiyo & Chitiyo, 2019; Mthombeni & Nwoye, 2018, Nyoni, 2011). Some of the challenges includes limited access to ASD services such as education (Chitiyo & Chitiyo, 2019) and health (Mthombeni & Nwoye, 2018). Parents did not understand the meaning of ASD from the African traditional perspective because the term autism does not exist in African cultures (Mthombeni & Nwoye, 2018). This resulted in parents using harmful methods of controlling the behaviour of the child (Chitiyo et al., 2019).

Apart from having challenges in understanding the cause of ASD, parents equally experienced barriers in accessing early treatment and intervention. Some children could only access early

intervention after the age of five and above (Nyoni and Serpell,201). The easily available early intervention services are normally available in special schools (Chitiyo & Chitiyo,2019). This means that children in areas where there are no special schools have continued to face challenges of accessing early interventional services.

Parents in Southern African region are also affected by limited finances. Studies conducted in South Africa showed that parents face challenges in accessing finances (Sandy et al., 2013). In addition, many parents cannot afford to hire caregivers. A study conducted in South Africa indicate that many parents had limited access to respite care (McKenzie and McConkey,2016) services. It was not clear whether parents in Zambia face similar challenges.

3.5.4 The burden of caring and raising a child with ASD among Zambian families

This section incorporated the literature from other disabilities because there was scarce literature in Zambia that explicitly mentioned the burdens associated with caring for an ASD child.

Raising and caring for a child comes with its challenges. This is because it is the most affected group in the world that is discriminated and has limited access to quality education, health, and social services (World Health Organization, 2011). These parents faced different types of burdens which includes poor access to education and health services (Nyoni & Serpell, 2012).

Many families in Zambia hardly visit health centres to access disability services because of the low number of skilled health personnel handling disability cases (Magnussen, 2011), and the poor doctors and nurses population ratios of 1 to 15000 and 1 to 1500, respectively (Makasa, 2009). Other barriers include long distances to health care facilities, high costs of transport, and high poverty levels (Magnussen, 2011). Such figures made it difficult for professionals to provide quality services. This trend is mostly common in rural areas where services are limited.

A qualitative study by Nyoni and Serpell (2012) revealed the shortage of health professionals which resulted in parents becoming exposed to a long waiting time before visiting a medical doctor. Interestingly, those professionals who were available gave conflicting statements about the cause of ASD, treatment, and diagnosis (Nyoni, 2011). This increases the burden of accessing mental health services. Apart from these burdens, mental health services have received little support from the Zambian government and society (Kapungwe et al., 2010;Mayeya et al.,2004; Mwape et al., 2010). For example, only 0.4 % of the national health budget was allocated to mental health services (Kapungwe et al., 2010). The inadequate funding to mental health services revealed how mental health services were perceived among policymakers.

Equally, access to quality education is a challenge to learners with disabilities. Studies in Zambia have shown that children with disabilities receive poor quality education (Malungo et al., 2018; 2019; Ndhlovu et al., 2016). The contributing factors included teachers' negative attitudes towards teaching children with special education needs (Serpell & Jere-Folotiya, 2011). Most special teachers in public schools preferred teaching the mainstream classes because of the financial motivation attached to teaching mainstream classes (Serpell & Jere-Folotiya, 2011) such as extra duty allowances. Other factors were limited teaching and learning materials, and limited pedagogical skills by mainstream teachers on how to teach learners with ASD in an inclusive classroom (Serpell & Jere-Folotiya, 2011). In addition, teachers may underestimated the potential that children with disabilities possess (Chataika et al., 2012).

However, despite barriers to education, a trace of success in teaching learners with ASD were observed in a study by Wonani and Muzata (2019). The authors revealed some significant support offered to parents of children with ASD by teachers at school (Wonani & Muzata, 2019). This was in contrast to two studies (Nyoni, 2011; Serpell & Jere-Folotiya, 2011) in which it was observed that some specialised teachers had a negative attitude towards education for learners with ASD. Some teachers prefer teaching children with other forms of disability and not ASD children. Teachers need to be trained on how to appreciate the potential in children with disabilities (Chataika et al., 2012). Additionally, the Ministry of General Education in Zambia should embark on sensitisation programmes for educating children with ASD (Wonani & Muzata, 2019). The campaign should not only target schools with ASD children, as recommended by Wonani and Muzata, but all mainstream schools, the general community, and mostly single parents.

It was evident that single parents in Zambia were mostly stressful as they had to juggle multiple responsibilities. The responsibilities which included overseeing school work and caring for a child with ASD (Wonani & Muzata, 2019). Wonani and Muzata (2019) observed that parents of children with ASD were able to access support from the communities and family members. However, the authors did not mention for how long the support was provided to parents. Furthermore, the sample population used was small and only targeted the educated parents. Nonetheless, for parents to cope with the challenges of raising a child with ASD, they require to have awareness knowledge on how to advocate for ASD services in Zambia.

3.5.5 ASD understanding and awareness in Zambia

This section discusses the understanding and awareness ASD by Zambians. It gives insight about the public knowledge of ASD in Zambia, stigma and discrimination and the existing policies that are aimed at helping parents access quality services.

3.5.6 Public knowledge about ASD in Zambia

A review of publications in Zambia on ASD showed relatively few publications that highlights ASD awareness (Chansa-Kabali et al., 2019; Macha et al., 2020; Nyoni, 2011; Nyoni & Serpell, 2012; Washington-Nortey & Serpell, 2021; Wonani & Muzata, 2019). This is worrying because studies have shown that individuals who live in a society that has limited information, understanding and awareness about ASD contribute to a negative impact on the health wellness of the ASD child and the family (Cloete & Obaigwa, 2019). This is because many parents and the general community may not know where to access treatment and diagnosis.

Chiluba and Njapawu (2019) conducted a qualitative study of 8 persons with disabilities where they examined public knowledge about the implementation of part five of the Zambia Disability Act of 2012, regarding public buildings in Lusaka. The findings revealed limited awareness about the Disability Act among policy implementers. The author observed that many contractors could not construct buildings that friendly (Chiluba & Njapawu, 2019). This could be the reason why most of the building in Zambia are not disability friendly which include institution like the university of Zambia. Another phenomenological- qualitative study among 17 educated Zambian parents of children with ASD was conducted in Lusaka, Zambia. The results equally revealed that many Zambians were not aware of ASD, its cause, treatment and diagnosis, and did not know where to access the services, and manage and raise a child with ASD (Nyoni & Serpell, 2012). The study also revealed that limited knowledge and understanding about ASD was evident across community members, immediate family members and siblings (Nyoni & Serpell, 2012). Equally, it was observed that there was limited knowledge and understanding about ASD even among professionals. For example, a survey examining ASD awareness and knowledge among 488 University of Zambia undergraduate students reported that seventy-nine percent (79%) of the students who participated in the study had never heard of ASD before the survey (Chansa-Kabali et al., 2019).

The most surprising finding in the same study was that students in the School of Education had significantly higher awareness levels than the medical students (Chansa-Kabali et al., 2019). The authors further observed that 61.9% of the participants did not experience ASD in real life, but were exposed to the condition through television and books, 3.8% knew someone in passing and

via hearsay, and 4.8% did not have any experience with ASD (Chansa-Kabali et al., 2019). The insufficient awareness and understanding of ASD in Zambia resulted in the community developing a negative attitude towards parents of children, wrongly labelling the child and neglecting the feeling of parents who equally had higher expectations for their children with ASD (Washington-Nortey & Serpell, 2021) to live an independent life.

One way of rethinking was to take advantage of World Autism Awareness Day. In 2017, the United Nations (UN) selected April 2nd as a global World Autism Awareness Day (UN General Assembly, 2007). The aim is to increase ASD awareness. Despite this initiative by the UN, many member states like Zambia hardly takes this opportunity to increase ASD awareness. Additionally, there is a need to publish data in Zambia highlighting parents' leading role to promote ASD awareness during the ASD awareness month. Another strategy is to make parents aware and knowledgeable of their human rights as enshrined in the Zambia Disability of 2012. Parents, with the support of other stakeholders, were required to take multi-task approaches and engage various stakeholders such as churches and media houses to initiate awareness campaigns on disability. ASD awareness promotion can equally be done through continuing professional development (CPDs) within the institutions. Furthermore, researchers need to use culturally set research that promotes ASD awareness on the importance of early intervention and the need to access education and psychological services (Kang-Yi et al., 2018).

3.5.7 Stigma and discrimination towards parents and children with ASD

They are similar studies conducted in Africa that have revealed that many parents of children with ASD experience stigma and barriers to access ASD support services (Gona et al., 2016; Tekola et al., 2020; Tilahun et al., 2016).

Studies in Zambia indicates that generally, parents of children with disabilities live isolated lives and are discriminated because they were not aware of the existing non-governmental organisations that provided disability support. A Zambian National Disability Survey of 2015 report showed that people with disabilities had limited awareness regarding the existing Disability Peoples Organisations (DPOs) (The Government of the Republic of Zambia, 2018).

The limited knowledge about DPOs may have contributed to current national policy documents which are not inclusive to ASD disability issues but give prominence to physical disabilities and body functional disabilities (The Government of Republic of Zambia, 2010; The Government of the Republic of Zambia, 2017). Intellectual and mental health-related conditions were

categorised under one as one disability in contrast to visual, physical and hearing impairments that are treated independently (The Government of Republic of Zambia, 2010, 2017).

The non-availability of information for disabilities such as ASD in policy documents perpetuates discrimination regarding ASD services. According to the United Nations report on disabilities in Zambia, many persons with disabilities were not involved in decision making, how policies are made and even in community and political aspects (United Nations General Assembly, 2017).

Accessing therapy services can be a result of limited understanding and awareness of ASD. There are insufficient publications in Zambia that have highlighted the type of therapy services that children with ASD access, unlike in developed nations where Applied Behaviour Analysis) ABA, TEACCH and BEI are used (Dixon et al., 2019; Lim & Draper, 2011). The lack of adequate knowledge and awareness about ASD frustrates parents on how to assist the child to reach the highest potential in life such as in areas of education (Wonani & Muzata, 2019). This is because of the counter accusation between teachers and parents. Teachers often accuse parents of having a negative attitude towards the education of a child with ASD (Wonani & Muzata, 2019). However, parents equally blame teachers for their negative attitude towards educating children with ASD (Nyoni, 2011). Mutual recriminations between teachers and parents affects the type of education the child can access and, in most cases, a child accesses poor quality education service. This calls for rethinking how ASD services are provided in Zambia.

The insufficient knowledge of ASD resulted in parents seeking ASD services from various service providers such as medical, religious, and African traditional healers' multiple times. This approach can be costly, distressing, time-consuming, increase parents' desperation to have their child cured and contribute to delays in accessing early intervention therapy services (Nyoni, 2011).

3.5.8. Understanding disability policies in Zambia

Zambia has many laws that relate to the welfare of persons with disabilities. Some are treaties and conventions that Zambia signed with international agencies. At a global level, Zambia has ratified many conventions such as the Convention on the Rights of Persons with Disabilities in 2008 with the United Nations Human Rights Convention. At a local level, many policies that speak on disabilities were enacted. This included the 1996 amended Republic Constitution (The Government of Republic of Zambia, 1996), the Mental Health Act of 2019 (GRZ, 2019); Disability Act of 2012 (Government of Republic of Zambia, 2013) and Education Act of 2011 (Government of Republic of Zambia, 2011). These laws and policies help families of

children with disabilities access the needed support services. Laws like the Persons with Disabilities Act 2012 gives power to people with disabilities to access free primary education (The Persons with Disabilities ACT, 2013).

A study by Sibanda (2016) surveyed the impact of the free primary education policy on the education of learners with disabilities in inclusive and special schools in the Lusaka district of Zambia. Sibanda sampled 56 respondents, four head teachers, 20 teachers, 20 learners with disabilities, and 12 parents. Her results showed that, despite having a policy on free primary education, parents had to pay other fees. The fees were determined by the Parents' and Teachers Association (PTA). The high fees hurt parents as they could not afford them, hence forcing the child with a disability to drop out of school. The study employed a Critical-emancipatory theoretical model that highlights how parents developed critical thinking on issues affecting them.

Social justice is critical to the provision of education services where preferences are given to typical children than those with disabilities (The Government of Republic of Zambia, 2017). The majority of children with disabilities are out of school, while others are confined to special schools and units (Ndhlovu et al., 2016). Parents required Critical-emancipatory skills and knowledge on how to access available limited services as they advocate for equity to service provision. Disempowered Zambian parents may experience challenges to confront barriers to support services such as defiance teachers, poor teacher-pupil ratio, and unfriendly infrastructures in the community as most children with autism attend special schools as opposed to mainstream. This was in contrast with Ireland where, in the last ten years, most children with intellectual disabilities are in inclusive mainstream classes (McConkey, et al., 2015). These parents may not know and understand the rights for a person with a disability to quality education as enshrined in the United Nations human rights for persons with disability documents (Convention on the Rights of Persons with Disabilities, 2016; United Nations Children's Fund (UNICEF), 2006). Despite having the policy documents such as the Zambian Disability Act (The Persons with Disabilities (Amendment) Bill, 2013) (GRZ, 2013), The Constitution (GRZ, 1996b) and many other human rights, these documents become of limited use when the resources are not available. This has in the end disempowered parents as they cannot access equitable education services provision and equal resource distribution.

Health policies of free quality health services for children with ASD are not very clear. No law in Zambia compels the government to provide the services according to the needs of a person with disabilities and their families. For example, the Mental Act of 2019 and the Disability Act of 2012 policies do not spell out what punitive measures would be meted out against institutions that do not accept children with ASD or charges fees. A study conducted in the Mazabuka District in the Southern Province of Zambia that investigated factors perceived by caretakers as barriers to health care for under-five children showed that medical services were costly for an ordinary Zambian. The results further showed that mothers paid K500 (US \$.50) for registration and K2000 (US \$200) for consultation and medication, and mothers were charged a penalty fee of K6000 (US \$600). These costs hindered most parents from accessing equitable health services as they are no law that regulates the costs of accessing health services. Each institution may come up with their own costs according to their economic challenges that they may face.

The insufficient information in the policy documents about ASD and how to protect the rights of a child with ASD and the family has resulted in parents facing challenges in accessing different services such as education, health, and social services. This has further contributed to increased red tape and bureaucratic process, unresponsive management systems at all levels of accessing the services, inadequate development of new health workers, and geographic maldistribution (Gow et al., 2011). Unfortunately, the most affected groups are families of children with disabilities in rural communities (Halwindi, Siziya, Magnussen, and Olsen, 2013). Parents need to play a direct and indirect role in policy advocacy regarding ASD services. According to disability activists, any decisions made on disability issues such as policy matters that exclude the affected group and are enacted by a person with limited experience and knowledge about the condition are a violation of the rights of the affected group (Barnes, 2003). Such policies might not speak the language of the affected group. For example, *Educating our Future Policy* (The Government of the Republic of Zambia, 1996a) which compels all learners to access diagnosis and assessment before starting Grade 1 was hardly actualised in schools. Most children who started school in 1996 to date have had lower access to early assessment before starting Grade 1.

To mitigate such challenges in a society like Zambia, the current study explored whether the use of the PAR approach would be an appropriate tool that would empower parents themselves to take the lead on barriers and hindrances to support services and find out whether it could be a cost-effective and sustainable approach to promoting awareness among the parents themselves and the community. The use of PAR is critical as it will help understand professionals' experience with formal support services provided to parents of children with ASD as discussed below.

3.6 Professionals ‘experiences in providing formal support services to families of children with ASD

This section highlights how ASD treatment and diagnosis was perceived by parents from the medical, religious, and African traditional perspectives. The professionals who provided formal support services include medical, religious leaders and Africa traditional healers.

3.6.1 Medical Professionals ‘experiences in providing formal support services to families of children with ASD

Historically, early Medical ASD knowledge and diagnosis is traced from the United States of America and Europe (Greydanus & Toledo-Pereyra, 2012; Kanner, 1943) where its treatment was associated with Western medicines (Evans, 2013; Fong & Lee, 2017; Greydanus & Toledo-Pereyra, 2012). The diagnosis and treatment of ASD were done by psychiatrists, psychologists, and neuroscientists (Baron-Cohen, 2015; Evans, 2013; Kanner, 1943). To date, ASD is still diagnosed by certified medical scientists who use different tools that fall within the two categories of (1) the Diagnostic Statistical Manual (DSM) (American Psychiatric Association, 1987, 2013), and (2) the World Health Organisation International Classification of Diseases (ICD-10). These two manuals are the world’s most used manuals to classify mental disorders from a medical perspective. Health professionals often perceived autism as a medical problem. The core focus of ASD scientists is to understand how the brain of people with ASD functions as compared to a typical brain of a person without a disability (O’Dell et al., 2016).

The scientific approach of understanding how the brain works proved to be a challenge to non-Western countries where the term ‘ASD’ does not exist in their culture and religions. Mthombeni and Nwoye (2018) found that, among black South African caregivers the term ‘ASD’ did not exist in their culture and that the use of Western approaches in treating autism spectrum disorder symptoms yielded little benefits. A qualitative study conducted in the USA among Korean American immigrant communities in understanding how community-cultural beliefs affected the care for ASD children with autism revealed that community beliefs influenced the understanding of autism by families and professionals (Kang-Yi et al., 2018). Understanding an individual’s culture during ASD diagnosis and treatment is very important. This is because professionals who treat and diagnose ASD might have equally limited knowledge on how to use different Western diagnoses and treatment tools that may not be culturally appropriate.

In trying to meet the diagnosis tool crisis in many African countries of which most of the tools have copyright patents and are expensive to access (De Vries, 2016), some scholars have translated the tools into local languages intending to make them cultural friendly and appropriate

to meet the local community diagnostic needs. Smith and colleagues (2016) translated an Autism Diagnostic Observation Schedule-2 assessment tool into Afrikaans for the ‘coloured’ population from low-middle socioeconomic status backgrounds in the Western Cape Province, South Africa. The findings revealed that the tool met the criteria to be used in other cultures. However, the researchers observed that there were some gaps in the cultural meaning of words like ‘emotions’ in Afrikaans, which had a different behavioural meaning in the West (Smith, Malcolm-Smith, & de Vries, 2016). Human individual emotional perception in each cultural setting can lead to the wrong diagnosis, treatment, and labelling of children with ASD. For example, ASD treatment in the West has more to do with behavioural and sensory relations and cognitive observations, use of pharmaceuticals, administering of vitamins, and diet therapies (Zhang, 2010). This is different from non-western cultures, whose treatment has more to do with administering herbal medicines (Zhang, 2010).

Caron and friends (2012) compared the frequency of parent-reported responses to sensory experiences in children from two countries—Israel and the United States. The authors administered the Short Sensory Profile to primary caregivers of children with autism spectrum disorders (ASD) and typically developing peers. The results indicated that Israeli parents reported unusual responses to sensory experiences less frequently than US parents for both ASD and typically developing children. The results further revealed that US children with ASD demonstrated significantly greater difficulty in the Auditory Filtering and Visual/Auditory Sensitivity domains than Israeli children with ASD. These findings support the influence of culture and environment on caregiver perceptions of the responses to sensory experiences of children with ASD (Caron et al., 2012). The study by Caron and friends (2012) has shown that although the Westernised classification and diagnostic systems may be available and used by different clinicians in different cultural settings in communities, it was not guaranteed and does not mean that all children will be correctly diagnosed or that their symptoms will be conceptualised according to diagnostic criteria. Therefore, clinicians need to understand and appreciate cultural variations when diagnosing and treating ASD.

Professionals with more Western experience in diagnosing and treating ASD should not concentrate on therapies that are only behavioural related but also holistic. Professionals need to be aware of how culture influences the diagnosis and treatment of ASD (Ennis-Cole et al., 2013). Furthermore, professionals need to be culturally sensitive when dealing with communities that are non-western to avoid assuming that ASD treatment and diagnosis are universal (Neeraja & Myers, 2013). Medical doctors require robust training in community cultural diversity about

ASD services (Woolley et al., 2013). The training can assist the professionals respect the views of the parents and get into a mutual understanding on how diagnosis and treatment ought to be done. The treatment and diagnosis may include both a combination of biomedical and cultural practices (Ravindran & Myers, 2012).

Therefore, professionals and parents need to have a deep understanding of both Western scientific treatment and African cultural knowledge (Mthombeni & Nwoye, 2018). This is because ASD is differently constructed by various cultures (Kim, 2012).

Professionals should not only respect knowledge from their own acquired academic studies but also local knowledge. This knowledge may be of low intensity in nature but it is critical in a child's diagnosis, treatment and care. Reichow et al. (2013) acknowledges that even low intensity parent-mediated interventions can be effective.

The limited understanding of ASD treatment from the Western perspective led parents to seek service from African traditional healers.

3.6.2 African traditional healers' experiences in providing formal support services to families of children with ASD

Although much of the research studies on ASDs have been conceptualised and conducted in the Western countries, mostly the United States of America, in the years leading up to this research, there is insufficient data that has explored how ASD is diagnosed and treated from an African traditional healers' perspective. Some publications have attempted to explain the role of culture in ASD diagnosis and treatment across different cultures in other parts of the world (Cui & Elizabeth, 2012; Mandell & Novak, 2005; Munroe et al., 2016).

The role of African traditional herbalists or healers in the treatment and diagnosis of ASD has not fully been explored. Much of the literature considers the cause of ASD to be demons and witchcraft. This is because it is a spiritual world that affects the quality of human life in the physical world (Zambia Mental Health Users Network, 2014). Health-related conditions that cannot be explained by the community are linked to natural causes and supernatural powers in the spiritual world.

Traditional healers have their understanding of the diagnosis and treatment of ASD from an ancestral spiritual to a physical perspective. This is because they have a limited scientific understanding of ASD (Bakare & Munir, 2011; Gona et al., 2015; Nyoni & Serpell, 2012; Samadi & McConkey, 2011; Tripathi, 2015; Yu, Stronach, & Harrison, 2020). This may have contributed

to limited knowledge about family support needs and perpetuated discrimination, stigmatisation and associating ASD with witchcraft or demons (Cloete & Obaigwa, 2019; Gona et al., 2016).

The linking of ASD to traditional beliefs made it more challenging to diagnose and treat ASD from both Western and African traditional perspectives because of a different understanding of the diagnosis and treatment approaches. Reviewed literature on the cause of ASD and treatment in many African countries showed a similar pattern of associating the cause of disabilities to supernatural powers and cultural beliefs. A study in Kenya involving twenty-four participants showed that the cause of ASD was not only associated with witchcraft but also inter-tribal marriages (Cloete & Obaigwa, 2019).

Ndubani and Hojer (1999) conducted a qualitative study on the role of traditional healers in the rural Chiawa part of Zambia. The authors discovered that the rural community believed that traditional healing was part of their culture which cannot be taken away from them. This is because culture influences the traditional beliefs and customs that one holds and are transmitted to the next generation using various modes of transmission (Matsumoto, 2006).

Parents of children with ASD are no exception in seeking services from traditional healers. This is despite many Zambians still seeking the services of the (witchdoctor) Si *Ng'anga* under secrecy. This is because *Ng'anga* practitioners are still considered as an occult group who practice magic and witchcraft and have an evil connotation in the community (Sugishita, 2009). Majority of Zambians have knowledge of the services of traditional healers and unconventional medicine. However, very few Zambians publicly access the services of *Ng'anga* or unconventional medicine. This is because they fear to be victimised by religious groups and medical health professionals (Sugishita, 2009). This strong belief in traditional medicine by the community may be difficult to be appreciated by Western world medical practitioners because of what they call the lack of scientific evidence.

However, the use of traditional healers' services and herbal medicine is on the increase despite some apprehension as to its safety, quality and its scientific proof (World Health Organisation (WHO), 2013a). The Disability Human rights report in Zambia indicated that there is a demand for traditional healers in Zambia. This is seen by the many adverts placed in different print media newspapers and adverts in many walls of buildings. The adverts talk about providing services on mental illness, bringing back missed lovers, and making some rich. These traditional healers are further located in local communities, and could easily be accessed and are readily available to attend to complaints of the clients (Zambia Mental Health Users Network, 2014).

Another qualitative study in the western part of Zambia revealed that parents could easily access services from traditional healers as compared to medical health services (Stekelenburg et al., 2005). Kromberg and colleagues (2008) reported that parents in South Africa were able to easily access the services of traditional healers to assist in the treatment of ASD. A combination of herbal medicine and conventional medicine has been shown to improve autism treatment (Bang et al., 2017). Understanding ASD from the cross-cultural African healing perspective proved difficult to parents who still felt disempowered because they could not receive appropriate support.

However, studies revealed some of the benefits of understanding ASD from a cultural perspective. Daley (2002) points out several benefits of understanding ASD from a cultural context. The first is the understanding of cultural differences and variations that ASD systems may present. The second was the understanding of what is normative in human development in different cultural contexts. Lastly, researchers were able to study autism from a cross-cultural perspective. This increased our understanding of the meaning of ASD and what is attributed to diagnosis across the world (Daley, 2002). However, parents who may feel that the traditional healers' services lacked a definite cure, they quickly joined another circle of visiting religious leaders in the search for support services.

3.6.3 Religious leaders' experiences in providing formal support services to families of children with ASD.

Religion, like culture, is deeply entrenched, and it is difficult to separate an individual from his or her religion. Religion plays an essential role in how an individual makes decisions in accessing disability services. From the African perspective, religion is part of life. Leonard observed that:

The religion of these natives [Africans] is their existence, and their existence is their religion. It supplies the principle on which their law is dispensed, and morality adjudicated. The entire organisation of their common life is so interwoven with it that they cannot get away from it. Like the Hindus, they eat religiously, drink religiously, and sing religiously (Leonard, 1966, p. 429).

Mbiti (1969) further states that:

A person cannot detach himself from the religion of his group, for to do so is to be severed from his roots, his foundation, his context of security, his kinships, and the entire group of those who make him aware of his existence (Mbiti, 1969, p. 2).

Religion and culture are like “conjoined twins”, emphasising their strong connection to each other (Pitten, 2008; Osewska, Stala & Bochenek, 2021). Studies revealed that religion plays a critical role in the lives of many families who have children with disabilities due to its supportive framework that provided an anchor to cope with life’s challenges (Bennett et al., 1995; Skinner et al., 1999). A study explored the role of Pentecostalism on disability in Zambia. Six video recordings from three Pentecostal churches showed that participants believed that spiritual leaders had the power to heal disability and cure it through prayers. The assurance of the healing power of prayer for a child with a disability may offer hope to parents and increase their faith in God, as they search for answers to the cause of the disability. However, the study by Mwale and Chita (2016) failed to indicate which type of impairments were healed through prayers. In addition, the data collection tools of using videos might not be more appropriate in cultures where speaking on camera may still be a challenge and created an artificial scene for most participants. However, the study highlighted how faith, was part of the healing process among families of children with disabilities. Faith and prayer showed a relationship between religion and how disability services are perceived by the family (Jegatheesan et al., 2010).

In Zambia, it was observed that parents had a strong faith in clergymen and women to heal a person with a disability. This is because the clergy are seen to have divine power to cure disabilities (Mwale & Chita, 2016) and are mediators between God and people (Stekelenburg et al., 2005). The clergy use biblical principles when practicing exorcism (Mpofu & Harley, 2002). Therefore, parents’ religious faith helped them to attain high levels of spirituality (Skinner et al., 1999). In this study, it was important to investigate whether faith and prayer had a role in the healing process of parents of children with ASD. This is because the strong religious belief among Zambians is supported by the 1996 constitution which declared Zambia as a Christian nation (GRZ, 1996) with majority 95% of the population being Christians, and less than 4% representing other religions - Islam, Hinduism, and African Traditional Religions (ATR) (Government of Republic of Zambia, 2012).

Studies have shown that parents of children with disabilities with higher spirituality levels use it to find the meaning of their suffering and misfortune in life (Jegatheesan et al., 2010; Weisner et al., 1991). An online study that examined the association between spirituality and anxiety among 73 Christian mothers of children with ASD revealed that these mothers stated that their children with ASD provided a positive contribution to the family’s social well-being (Ekas et al., 2019). In another qualitative study, mothers of children with ASD who actively participated in religious activities had improved psychological well-being and were better able to handle a child with

ASD (Ekas, Tidman, & Timmons, 2019). Similarly, another study conducted in 15 countries showed that parents of children with ASD who accessed spiritual intervention sessions showed greater resilience in coping with life's challenges (Pandya, 2018).

The sources of the coping mechanism include prayer, attending church services and some specific religious beliefs (Bennet, Deluca & Allen, 1995). The studies above show that religion plays a critical role in stress management and acceptance of the child's ASD condition.

As much as parents used different mechanisms to develop resilience and cope with stressors, parents who desired to maintain a religious life together with the child with ASD faced many barriers from the church community. A study by Tarakeshwar and Pargament (2001) reported that parents were stressed because the church could not provide respite care support services and discriminated against children with ASD. In some instances, parents were forced to leave their children outside the church because of discrimination (Coulthard & Fitzgerald, 1999). Other barriers that parents faced were associated with the child's severe behaviour that hindered parents from attending church services (Tarakeshwar & Pargament, 2001).

This was coupled with insufficient knowledge by religious leaders about the child's ASD condition (Coulthard & Fitzgerald, 1999). The reviewed literature shows that parents of children with disabilities who receive spiritual support from the community of faith have higher chances of coping with the condition as compared to those who did not (Richie, 2015).

Richie (2015) suggested that parental stress can reduce by educating religious leaders about the various types of disabilities. Additionally, religious leaders needed to be involved in future action research that deals with ASD and family support services. Such a strategy might influence religious leaders to develop curriculums that promote the theology of disabilities (Richie, 2015). In a paper by Ritchie (2015) on the need for the church to educate children with disabilities, he observed that the low knowledge among the community of faith in educating children with disabilities was associated with a lack of adequate theologies developed on disability (Richie, 2015). Thompson linked it to a lack of a religious education curriculum tailored for persons with disabilities such as ASD (Thompson, 2019).

The insufficient understanding of ASD by religious leaders increased higher levels of stress among parents of children with ASD and forces some parents to lose faith in religious activities. Equally, parents who accessed medical and traditional healers' services observed that the services

accessed were inadequate and not definite. The methodology applied to empower parents in this study was apply PAR approach.

3.7 Application of PAR in Parents Empowerment.

In recent years, there has been a power shift in how health services are provided, from deficit-based to support-based approaches (Kyzar, Turnbull, Summers, & Gomez, 2012). The power shift is from professionals to parents. In the past decade, parents were left out in decision making regarding challenges affecting them. The power shift was a result of a revolt by persons with disabilities against traditional disability models such as the medical model, which had little regard for the role of a person with a disability and the family on treatment and diagnosis of a disability (Oliver, 1990). This shift is in line with the World Health Organisation that promotes a community-based rehabilitation approach which gave a voice to the affected group to have bargaining power on how they wanted services to be provided to them in their local communities (World Health Organisation, 2010b).

There are few studies in the field of autism in Africa that have considered evidence-based family support interventions using the PAR approach as an empowering tool. Tshabalala (2014) states that:

The process of supporting parents is viewed alongside the concepts of empowerment, transformation, and participation with the understanding that, given some level of support, one gains more power to do things one would not have been able to do in the absence of support (Tshabalala, 2014, p. 31).

As observed by Tshabalala, family support services must be aimed at transforming parents of children with disabilities to have more power to “do things one would not have been able to in the absence of support” (Tshabalala, 2014, p. 31). There were several benefits of an informal parent-led support group that employed the PAR process to address the problems affecting them. These include: (a) participants develop a feeling of being welcomed and being accepted to the group by fellow parents (Mandell & Salzer, 2010); (b) it acted as a buffer to improve psychological well-being and reduce stress (Law et al., 2001), (c) the group shares common experiences about ASD with each other (Law et al., 2001); (d) the group shares a feeling and sense of self-efficacy; (e) the interaction within the group increases confidence to deal with the daily struggles of raising a child with disabilities (Law et al., 2001); and (f) it provided experiential learning as they interact and address the challenges they face (Lorenzo, 2005). Literature has shown that participants that belonged to support groups demonstrated lower levels

of depression and stress when interacting within a parent-led support group (Benson, Daley, Karlof, & Robison, 2011; Wei et al., 2012).

Further studies showed that parents-led support groups assisted the affected group or individual to cope with their emotional, social, practical, and informational needs (Tehee, Hevey, Tehee, Honan, & Hevey, 2008; Stahmer et al., 2016). A study by Samadi, McConkey and Kelly (2012) in Iran among parents of children with ASD revealed that parents had a feeling of less stress, used problem-focus approaches to cope with challenges, had better emotional well-being, and improved family functioning. In Israel, families with a child with ASD came together to share their lived experiences and advocate for better support services for the child with ASD during the Bar Mitzvah rite of passage. The Bar Mitzvah is a public communal traditional rite amongst the Jews who initiate a child at the age of 13 into the Jewish adulthood community. Findings show that a parent-led support group was successful in helping a boy with ASD to be included in the Bar Mitzvah rite of passage (Mia, 2009). In another study conducted in the USA, a parent support group collaborated with the researcher in fun day activities that brought families of children with ASD together. The researcher discovered that parents and child well-being improved (Lock, Hendricks, Bradley & Layton, 2010). Parent-led support groups promoted networking within the family support group and helped parents develop critical thinking, which enabled them to advocate for service delivery within a framework of inclusiveness, dialogue, hope, transparency, and engagement (Banach, Iudice, & Couse, 2010; Mulligan et al., 2010). Indirectly, local knowledge enabled researchers to translate their scientific evidence into practical terms (Yusuf & Elsabbagh, 2015) and improve the lives of the participants (Harper, Dyches, Harper, Roper, & South, 2013).

Furthermore, parent-led support groups benefitted from the local community. The local immediate physical and material environments and economic conditions of the local participants are transformed and improved. This is because parents' local knowledge is incorporated into the research process and is considered by researchers as necessary (Babbie & Mouton, 2012). The interconnection between parents and their local environment such as professional, family neighbours, school and church at the five ecological systems of Bronfenbrenner enhances personality development (Bronfenbrenner, 1994).

However, there were some weaknesses with the use of parent-led support groups. One primary concern about community-based (PAR) programmes in Africa is the sustainability of the projects after the initiator stopped supporting them (Mazibuko, 2007; Oino, Towet, Kirui, & Luvega,

2015). Another challenge of community-based is measuring the practical impact the project may have on the families. Developing training programmes tailored to local people can help sustain the project.

3.8 Summary of the chapter

The chapter has highlighted that Autism is a disorder that affects the neurobiological function of the metabolism of children (American Psychiatric Association, 2013). The condition affects many different aspects of a child's development in the physical, emotional, neurological, and psychiatric developmental stages (American Psychiatric Association, 2013). Many parents of children with ASD may not know about the condition of ASD until the child is about five years. This makes some parents delay in accessing early interventional services. ASD today has no single, specific universal cause and cure (American Psychiatric Association, 2013). Globally, ASD is on the increase (World Health Organisation, 2013b). Therefore, general health professionals and teachers from the mainstream, including social workers, need to have knowledge of ASD (Chansa-Kabali et al., 2019). Equally many Zambians were not aware of what ASD is, its causes, treatment, and behaviour management of the child (Chansa-Kabali et al., 2019; Nyoni & Serpell, 2012). This contributed to parents of children with ASD encountering various barriers to support services which include discrimination and stigmatisation from the community and professionals. Parents had to form support groups to address the barriers to ASD services. In the next chapter, I discuss how the data was collected.

CHAPTER FOUR

RESEARCH DESIGN AND METHODS

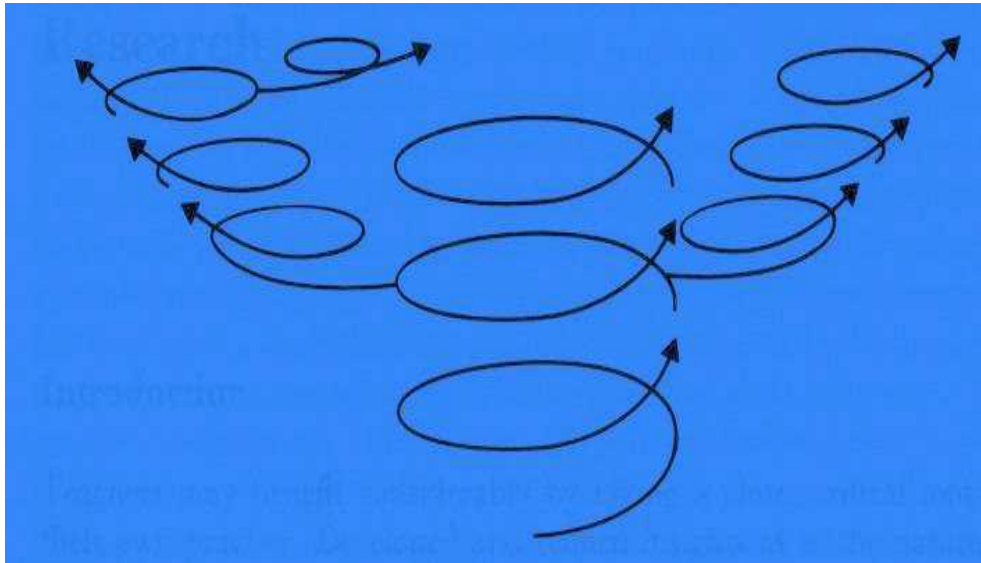


Figure 4-1: Action research spirals

“Cycles of action research do not tend to evolve in a neat sequential process, but a messy process of different cycles being in motion concurrently, as there being ‘spirals off spirals’, and concurrent cycles influencing each other” (McNiff, 2002, p. 56).

4.0 Overview

Chapter 4 describes the qualitative participatory action research (PAR) methodology, whose action cycles follow this “messy, but concurrent cycles” as observed by McNiff (2002). The chapter is divided into two sections. Section one explores the qualitative research design and how PAR was selected as an appropriate methodology. Section two explains how data was collected and analysed. Figure 4.2 shows how the chapter is structured.

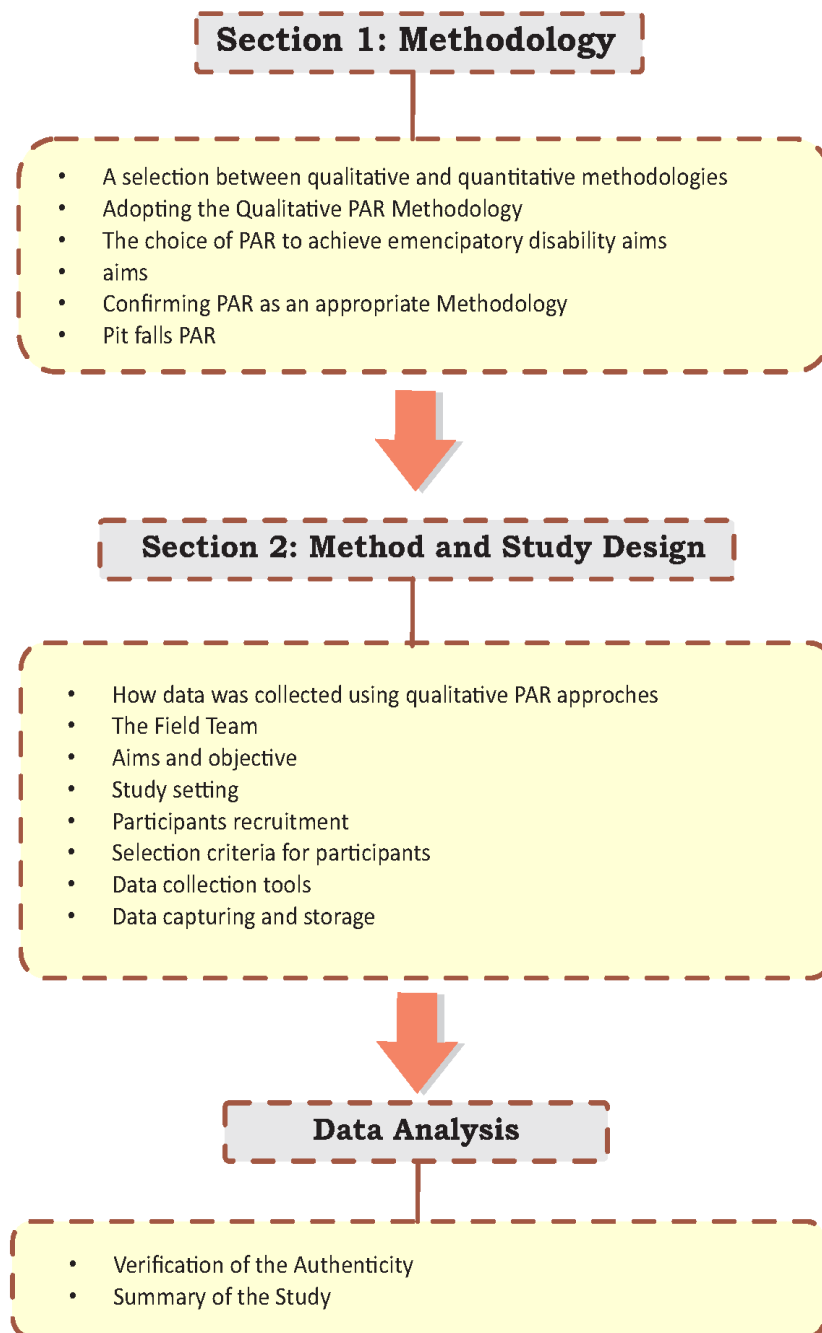


Figure 4-2: Structure of the chapter

4.1 Section 1: Methodology

Section one justifies why the qualitative research design, and the PAR approach were selected as appropriate methodology. The section further highlights studies conducted in both LMIC and developed nations that had used PAR approaches and whose results showed positive behavioural change among the participants. I further highlight some pitfalls that went with selecting the PAR approach.

4.1.1 Selection between qualitative and quantitative methodologies

Scientific studies are generally informed by a certain theoretical position enacted through methodologies. Research methodology is a “strategy or plan of action that shapes our choice and use of methods and links them to the desired outcomes” (Baum, 2006, p. 854). All research falls into two broad methodological categories of qualitative and quantitative research (Denzin & Lincoln, 1994). Qualitative research refers to verbal approaches which are used to collect data. The qualitative methodology aims at understanding a complex reality and the meaning of actions and behaviours that an individual portrays in each context (Clarke & Braun, 2013; Denzin & Lincoln, 2018). In qualitative methodology, the researcher works with the participants and data is collected with the view to understanding the behaviour and actions of the participant (Yin, 2016). The collection of numerical data is called quantitative research. The quantitative methodology focuses on obtaining accurate and reliable data where the researcher uses statistical analysis to analyse data (Clarke & Braun, 2013). In quantitative research, the researcher is independent of the data being collected (Cresswell, 2014).

4.1.2 Adopting qualitative research for this study

In this study, selecting qualitative research was appropriate because it provides a researcher with a platform to understand participants’ thoughts and the feelings that people ascribe to their experiences (Sutton & Austin, 2015). Studies have shown that human reality is best understood when the affected group is engaged in exploring, describing and interpreting their social world (Braun & Clarke, 2013). Denzin and Lincoln (2018) postulated that a deeper, socially constructive and interpretative meaning of participants’ experiences can be well understood when the researcher enters into the world of participants. Entry into the world of participants must be rigorous, systematic and practical and requires the researcher to become a co-learner with the participants (Stringer, 2014), and listen, observe, reflect and analyse participants’ actions and behaviours (O’Leary, 2017). Creswell (2014) succinctly states that “the longer the researcher stays in the ‘field’ or gets to know the participants, the more they ‘know what they know’ from first-hand information”(Creswell, 2014).

In this current study, I had to work with participants for ten months to gain first-hand information about their experiences with the unmet needs of ASD. The philosophical ontology and epistemology that underpin the research design were selected, that is, a single knowledge of truth is not possible. This is because human beings are social beings whose feelings and behaviours cannot be quantified or interpreted as a single reality. A constructivist theoretical approach is concerned with the production of meaning by people and the interpretation of the phenomena affecting them. Reality is not viewed as single but as multiple, because it is based on people's experiences. In this study, there was a need to understand the meaning of multiple realities obtained from the participants' words, behaviours, and actions. In this respect, a qualitative design was selected to prepare the researcher for "multiple possibilities" (Rubin & Rubin, 1995, p. 41) regarding the phenomenon affecting participants who directly get involved in dialoguing with the researcher and their local community. The qualitative design deals with the participants' constructed social meaning of their world and it enriches our understanding of human experiences in their environments (Denzin & Lincoln 2011, 2018; Patton, 2015, Strauss & Corbin, 1989). In addition, a qualitative approach enabled me to understand participants' experiences with prevailing ASD support services.

Using the qualitative approach, I was able to work with parents in their natural settings, observe their actions and how they were able to empower each through sharing their lived experiences. (See Chapter 5). This justifies why PAR was selected for this study.

4.2 The choice of PAR to achieve emancipatory disability research aims

Action research has been prevalent for over 80 years. It is not clear who first designed it. Lewin in 1948 was said to be the first person to have used action research in an inquiry that shifted from theoretical knowledge to capacity building (Carr, 2006; Greenwood & Levin, 2007). Other scholars believe that action research had its origins with Paolo Freire in the 1940s and the 1950s. Freire used it as a tool for political change, conscientisation and empowerment (Freire, 1972, 1982). In the 1980s, Fals-Borda used it for national agriculture development (Fals-Borda & Rahman, 1991) and later it was used in the health sector (Baum et al., 2006).

In this study, the PAR methodology is used in disability studies. PAR was selected because it operates on the basis that the affected individuals must directly participate at all stages of the research study. The parents of children with ASD faced multiple challenges in accessing support services. The challenges included limited access to diagnosis and treatment, distance to centres, limited awareness by professionals in the health, education, community sectors about the causes,

treatment, and diagnosis of ASD. In addition, parents had to deal with other siblings and other demanding pressures from relatives and work related. The applicability of PAR approach is that it gives power to the people and aims at promoting and achieving empowerment skills for participants (Baum et al., 2006). Power and the empowerment processes promote capacity development in the participants (Baum et al., 2006; MacDonald, 2012). PAR scholars engage local people directly in the projects, intending to find solutions to issues affecting them (Baum et al., 2006; Brún et al., 2016; Garza, 2013). The merits of PAR is that local people are assumed to be capable of designing programmes that bring social change in their local environments (McNiiff & Whitehead, 2006). This can be achieved through a collaboration between the researcher and the participants (Stringer, 2014).

PAR aims at empowering oppressed individuals to advocate for social transformation amongst themselves and the community (Gilbert, 2008; McTaggart, 1994). This is done by involving the affected groups in activities affecting them. Such groups work with the researcher to find a solution to the phenomenon. To achieve social transformation, the welfare of participants needs to be uplifted (Greenwood & Levin, 2007). This can be done through conscientisation and ‘awareness raising’ activities where the researcher is a facilitator and participants take up an active role to bring social change to the social situation affecting them in order to achieve the agenda set (Mertens, Bledsoe, Sullivan, & Wilson, 2010; Nueman, 2012). To achieve the set goals, appropriate social research tools such as interviews, focus group discussions and participant observations need to be used appropriately (Bless et al., 2009). The use of such tools enabled participants to freely express themselves during data collection (Cresswell, 2014).

Before adopting the PAR methodology, I felt it was prudent to explore other methodologies that would be suitable for this study. One such methodology was the participatory rural appraisal (PRA).

4.3 Participatory Rural Appraisal (PRA)

The Participatory Rural Appraisal (PRA), interchangeably called the Participatory Learning and Action (PLA), is another form of action research that enabled local people to “share, enhance and analyse their knowledge of life and conditions, to plan and to act” (Chambers, 1994, p. 595). In addition, the PRA methodology was influenced by critical theory and is closely linked to social justice (Chambers, 1994). PRA shared the principles of community-based participatory research (CBPR) (Chambers, 2002) which recognised the importance of outside intervention and collaboration on issues about which people could not meet at lower levels

alone. The PLA methodology aims at empowering participants in matters of improved decision-making, situational analysis, planning and evaluation of projects at the local level (Chambers, 2002). PLA has three common elements that assisted participants in actively getting involved in the study, namely:

- Self-aware responsibility: It advocated for individuals to take responsibility, develop self-critical awareness, and embrace errors when they occurred.
- Equity and empowerment: Participants must be committed to equity and empower marginalised groups.
- Diversity: It advocated for society to recognise and celebrate diversity (Chambers, 2002).

The above common elements spoke well to this study as they gave participants the power to communicate their views.

Another important characteristic of PLA was the use of action cycles during data collection. The PLA action cycles include sharing, enhancing, analysing, planning, and acting. The action cycles were achieved through diagramming, mapping and modelling; ranking and scoring; and problem analysis (Chambers, 2002).

However, despite all the merits of PLA, the methodology was not appropriate for this study because this methodology requires adequate time and resources to implement it. I did not have enough time and resources to use such a methodology since this thesis had an outlined time in which it was bound to be completed. The other gap in PLA was the emphasis to engage participants in identifying natural resources or the demographics of how health services were spread. Another gap of the PLA was involving participants in transect walks, whereas the local group walked in their respective communities to seek problems, solutions and opportunities to challenges affecting them (Chambers, 1994). In addition, PLA demanded that during data collection, participants be required to follow the chronological order of how the events happened and remember the precise date and time when the events occurred (Chambers, 1994). PLA departed from the aim of this study, which was to make meaning and understand barriers and hindrances to accessing ASD services.

However, there were many lessons that I learned from PLA. These include principles of community-based participatory research (CBPR), empowering participants in matters of improved decision-making, self-aware, responsibility PLA action cycles. These strategies resonated well with the study as discussed in sections 4.5 onwards and were included in my

methodology. However, despite the PLA methodology having some similar approaches like PAR, I opted for PAR because it uses multidisciplinary and multiform approaches to collect data. Secondly, using PAR approach was more culturally specific to Zambia's environmental settings regarding parents' experiences with ASD services. Therefore, I realised that I needed a methodology that does not operate from only one perspective for this research to claim authority and authenticity. In this study, I felt it was going to be a difficult task if I had used the PLA approach, as it is a narrowed approach as compared to PAR.

4.4 Confirming PAR as an appropriate methodology

In the current research study, I opted to select qualitative research in this field of disabilities because I wanted to understand parents' experiences with formal and informal ASD support services from a Zambian context. The qualitative approach was appropriate because its methodology is "rich, exciting, and challenging in lots of ways, it captures the complexity, mess and contradiction that characterises the real world, yet allows us to make sense of patterns of meaning" (Clarke & Braun, 2013, p. 10). In addition, qualitative research focuses on a phenomenon as it occurs in its natural settings, and involves studying that phenomenon in all its complexity (Cresswell, 2014; Leedy & Ormrod, 2010).

PAR was appropriate for this study because of its many benefits such as the promotion of the democratic process during data collection where data was collected from multiple participants who actively participated in finding the solution to the phenomenon affecting them. PAR allowed equity and liberated participants to construct their meaning of the phenomenon affecting them (Koch, Selim & Kralik, 2002). In addition, PAR used "a set of self-consciously collaborative and democratic strategies of generating knowledge and designing action in which trained experts in social and other forms of research work together" (Greenwood & Levin, 2007, p.1). I was further persuaded to use PAR, based on the work of different scholars. For example, a study by Radermacher (2006) explored the experiences of people with disabilities in Australia where she developed a strategic plan for Disability Justice Advocacy (DJA). She used the PAR approach to examine its value as an empowering research practice. Another study was conducted in Zimbabwe by Hope and Timmel (1995) who used the PAR approach to train participants on how to build structures, become self-reliant, and find the root cause of problems. In South Africa, Lorenzo worked with women with disabilities. The study aimed to "explore how disabled women living in poor communities equalise opportunities for human development and social change" (Lorenzo, 2005b, p. iv). She used the PAR approach to encourage disabled women to empower themselves and bring social change in the community and among themselves (Lorenzo, 2005).

Another study using the PAR approach was conducted in Kenya where the researchers developed a culturally relevant community-based intervention for children with communication disabilities (Hartley et al., 2009). Hartley and colleagues confirmed the benefits of PAR. Kramer-Roy (2015) used a participatory and creative methodology among Pakistan communities facing multiple disadvantages in the United Kingdom (Kramer-Roy, 2015). The successful stories above on the use of PAR in other countries were convincing and it was evident that the PAR approach could be applied in the Zambian setting.

PAR approach has been conceptualised as hermeneutic in this study. It has highlighted the felt needs and experiences of parents of children with ASD from the Zambian cultural context. It is through PAR methodology that parents identified ASD barriers to support services from the Zambian cultural context. See chapters 5 and 6.

4.5 Potential pitfalls of PAR

Despite selecting PAR, I was mindful that each research methodology had its weaknesses. Critiques of PAR stated that one of the pitfalls of PAR was that participants' interests might override group goals to achieve the set objectives (MacDonald, 2012). Another pitfall was the loss of interest in the study by the participants as the study progressed. This is normally a common situations where participants may not see any benefit of their participation in the study (Cornwall & Jewkes, 1995). This might be caused by limited knowledge on how the project was designed (Hornby, 1993), and participants' ability to influence the research answer on the phenomenon affecting them (Ward & Trigler, 2001).

Another school of thoughts emerging from some traditional researcher is that consider PAR as mere stories by participants (Duckett & Pratt, 2007). Such researchers have not put much weight on how PAR methodology is designed and implemented. Another limitation in the use of PAR was that it was not guaranteed that participants would keep all the confidentiality after group discussions, considering that, later the group would have contact with other community members.

To deal with the PAR pitfalls in this study, I came up with the following strategies. The first approach was to continuously remind participants about their role in the study as co-researchers whose aim was to emancipate themselves and find solution to issues affecting them. This approach acted as a deterrent to parents who might have wanted to use the study for personal interests or gains. However, since this was the first PAR research in this field, I observed that participants were ready to work as a homogeneous group with one agenda. The group agenda was focused on addressing issues of lack of ASD awareness in the society and how to bring social

change in the community. To avoid participants losing interest in the research study, I ensured that all participants took an active role and became co-researchers throughout the study.

To reject the thoughts by emergent traditional scholars who view PAR as many stories (Duckett & Pratt, 2007). I had to discuss how data was collected and linked it to the PAR approach. Parents formed a support group that went into the field to conduct awareness programmes and had reflective action meetings where parents shared their lived experiences.

4.6 Section 2: Methods and study Design

This section provides a detailed account of the research design in relation to PAR methodological frameworks. The section highlights how data was collected using a qualitative PAR approach. The first step that is discussed is how the research team entered the community. Later, I will discuss the aims and objectives of the study, stages of the action cycles, participants' recruitment in both Phases one and two, data collection and analysis. This section ends with verification of the authenticity of the data and ethical considerations.

4.7 The field teams

In this study, there were three facilitators. I was the primary researcher, working with two research assistants by the names of Henry Mwanza and Susan Chungu. The two research assistants were master's degree students in Clinical Neuropsychology at the University of Zambia. Both the research assistants were proficient in Cinyanja, the official language of communication in the Lusaka Province (Government of the Republic of Zambia, 2012). They also could code-switch in Chi-Tonga, Cinyanja, and English. Code-switching of language is common in everyday communication activities in the Lusaka Province because of many dialects and tribes that have been drawn from the ten major indigenous Zambian language groups (Serpell, 1980). To consolidate the knowledge of the research for the two research assistants, I conducted a one-day training programme to familiarise them with how the research study was going to be conducted. The content of the training was as follows:

- How to conduct interviews
- Respect for participants
- Confidentiality
- Counselling
- Ethics
- Data care, management, and storage
- Stipends
- Note-taking during interviews and fieldwork

I had to employ the services of research assistants because it was going to be a challenge to run the project alone, considering the time factor, resources, and distance to places where participants resided. Secondly, I needed people who knew about disabilities, mostly in the field of autism and who had vast knowledge of the local community and local languages. The two had more than five years' experience working with children with disabilities, including ASD. Thirdly, I wanted to start developing a cohort of future researchers who could use the PAR methodology. To check on the quality of work they were doing during the research, I would meet them and discuss how each assignment was completed. I also kept a record of their research activities.

4.8 Entering the community

Entering the community was not a big challenge. This was because I have lived and worked in the Lusaka Province for more than ten years. My work involves visiting schools and communities to monitor and evaluate education standards in Zambia. Working at the Ministry of General Education Headquarters under the Directorate of Early Childhood Education enabled me to interact with many parents, community leaders, and local and international organisations and stakeholders in the Lusaka Province and Zambia as a whole. Further, I once worked in the Assessment Centre at the Zambia Institute of Special Education (ZAMISE) for eight years. During this period, I interacted with different parents of children with disabilities who brought their children for assessment. Some of these parents were part of this study. Thus, I had prior knowledge of some of the locations, which were the source of the data I collected. Many parents were not dealing with a stranger but someone whom they knew or had heard of me on the radio and seen on television. This created confidence in the parents, knowing that they were not sharing their private information with a total stranger whom they did not know. To avoid parents feeling that the role I was playing was like the one I had at the assessment centre or the office, I explained to the parents that in this study my role was that of a facilitator and not someone who was assessing their children or policy maker and implementer. I have explained in detail the benefit of knowing the parents in my journal reflexivity in chapter eight.

I have been presenting programmes on disabilities both on radio and television and I have been involved in community outreach with persons with disabilities. Up until and during this study, I was involved in sporting activities, and I presented motivational talks in schools and churches. In addition, during my master's degree programme, I did a qualitative study whereby I worked with parents of children with ASD, some of whom became part of this study. This gave me more confidence to enter the field. In this study, parents saw me as a researcher who wanted to take a lead in promoting ASD awareness using research. Equally, professionals saw me as one of their

fellow researchers who was entering a research field that is hardly known and has limited publications in Zambia.

4.9 Research plan

The PAR research design had two phases, phases one and two. The aim of Phase one was to understand the experiences of the 73 parents of children with ASD as they shared their lived experiences of their unmet needs and shared the information about practical ways to manage their ASD children. Phase two had 17 participants who volunteered to continue with the study. These parents were selected from the initial 50 parents who participated in Phase one. The aim of Phase two was to identify the barriers to ASD services and to act using the PAR approach. This was done through a self-help, informal support group.

4.10 Aims of the study

1. Explore how parents experienced formal and informal services available in Zambia and what additional support services they would require and why.
2. Establish professionals' experiences in providing formal support services to families of children with ASD and what future support services they would desire families to access.
3. Understand how involvement in PAR activities supported parents' empowerment to meet the identified unmet needs of their children.

4.11 The objectives of the study as informed by PAR

The objectives of the study informed by the PAR were:

- Inquire into the nature of the problem in accessing formal and informal support services.
- Understand the significance of parent-professional and community collaboration in support services.
- Explore the benefits of forming a parent-led support group.

4.12 Defining action cycles

Stringer (2014) suggests that action research:

... uses continuing cycles of investigation that were are designed to reveal effective solutions to issues and problems experienced in specific situations and localised settings, providing the means by which people in schools, businesses, community agencies, and organisations, and health and human services may increase the effectiveness and efficiency of their work (Stringer, 2014, p. 1).

In this study, I adopted Kemmis and McTaggart's (1988) action cycle which has the principles of, planning, acting, observing, and reflecting. The four steps are linked and interrelated See Figure 4.3.

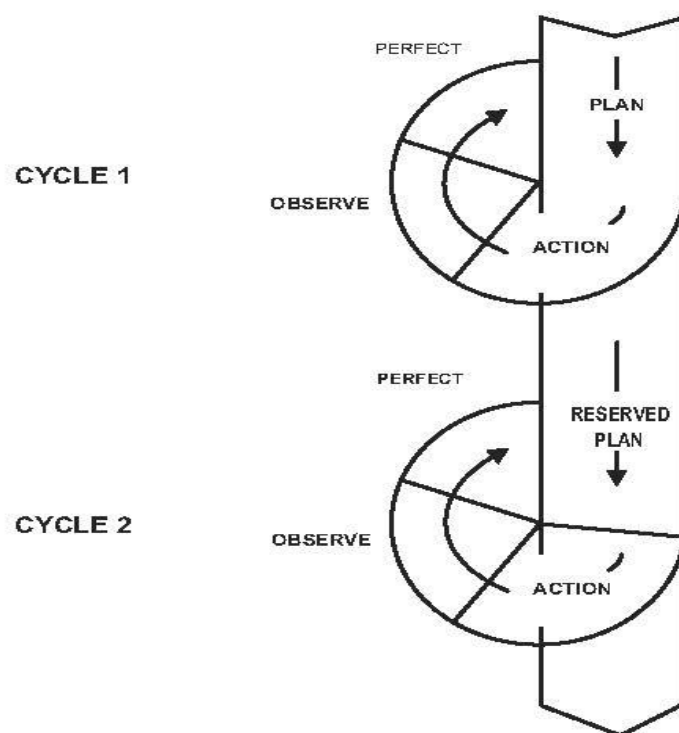


Figure 4-3: The action research cycles

The diagram above shows how the action cycles were implemented in this study. The diagram employs the principles of action cycles of Plan, Act, Observe and Reflect (Kemmis and McTaggart, 1988, p. 11).

4.13 The thesis design timeline

I had a timeline to help me get focused and finish the thesis on time. However, the time changed several times due to other barriers as observed by Clarke and Braun, (2013) who stated that:

One of the hardest things about research-especially qualitative research-is keeping on track and finishing it in good time. There are good reasons for this: recruitment can be difficult, data collection typically takes longer than we anticipate; transcription (if necessary) is time-consuming; and you just can't imagine how long it takes to analyse qualitative data until you've done it (Clarke & Braun, 2013, p. 68).

There were many challenges that I faced during this thesis; this include difficulty to get clearance for participants working in the government to be part of the study because of bureaucratic systems that are in place for a government worker to get permission and be cleared to be interviewed or be part of the study.

Other challenges included delays in starting the project because of conducting the study during the rainy season. Lusaka Province had cholera cases and the Ministry of Health had banned group meetings for 3-4 months. This delayed the study for over 4 months. When cholera was over, I had challenges of heavy rains as the study was conducted during rainy season. This meant rescheduling some meetings.

The most depressing challenge was the sudden closure of the University Teaching Hospital Developmental Interventional Clinic (DIC). This was the only public ASD Assessment centre in Zambia which was providing multi-disciplinary diagnosis and therapy services to children with ASD. The closure of the centre meant that I could no longer recruit parents or use its premises for meetings. The last challenge was financial resources which were equally limited. Meeting the costs of FGD and refreshments were a challenge due to the ever depreciating of the Kwacha against the USA dollar due to the delay in starting the data collection.

4.14 Sampling sites and informants

In this study, it is important to recognise the role played by participants, mostly the parents of children with ASD, as they searched for formal and informal support services. The population of interest was that of parents of children with ASD who were aged 2-14 years old, and who lived in the Lusaka Province. The other group of interest was that of professionals who provided ASD services to both parents and children and who lived in the Lusaka Province. Parents and professionals who lived in the Lusaka Province were targeted because, currently, it was difficult to recruit parents from other districts, mostly from remote areas outside the Lusaka Province.

After all, there was no statistical data or information from the Ministry of Health, Education, Community Development and Social Welfare and even the Central Statistic offices of children medically certified as having ASD children in other provinces except Lusaka.

In Zambia, most of the ASD Assessment Centres for diagnosis and treatment are in the Lusaka District. Secondly, most parents whose children were medically certified by health professionals as having autism live in the Lusaka Province for easy access to services. Thirdly, the Lusaka Province presented an ideal geographical and population location because it has a representation of participants from both urban and rural life settings.

4.15 The study setting

The study was conducted in the Lusaka Province of Zambia. The Lusaka Province is one of the ten provinces of Zambia. Lusaka is the capital city of Zambia, and the Lusaka District is the provincial headquarters of Lusaka Province. Lusaka Province has the smallest geographical setting covering only 21,896 km (The Government of Republic of Zambia, 2010) but with the highest population, estimated at 2,191,225, with a population density of 100 persons per km² as of 2010 (The Government of Republic of Zambia, 2010). The province shares boundaries with Zimbabwe and Mozambique and it has seven districts, namely, Lusaka, Chilanga, Kafue, Chongwe, Luangwa, Rufunsa and Chirundu. Chilanga, Chirundu and Rufunsa were new districts established from the year 2011.

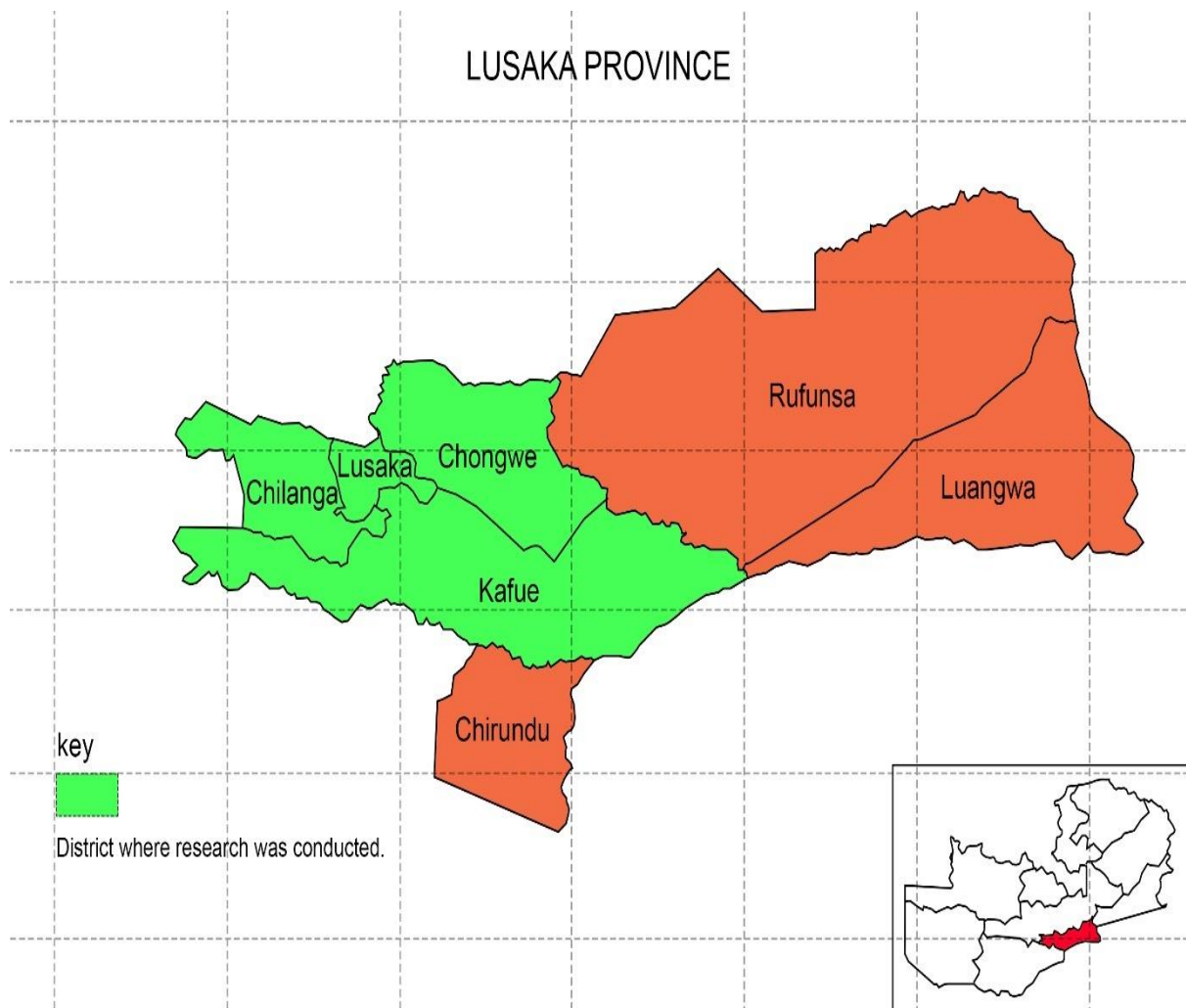


Figure 4-4: Map of Lusaka Province and the districts where the studies were conducted

**The Map was drawn by Mutembo Ndeke, a freelance art illustrator. Adopted with permission*

Five study sites were selected: Urban districts included: Lusaka and Kafue Districts. Two of the districts were rural - Chilanga and Chongwe. Purposive sampling guided the process. The sites were chosen to represent well-served and poorly serviced areas in relation to accessing ASD services such as education, health, social welfare, and programmes run by disabled people's organisations (DPO).

In Phase one, I selected participants with not less than three years of experience in caring for a child with ASD. Such parents would provide the needed information that met the objectives of the study. Purposive sampling was used to select 73 participants-50 parents and 23 professionals. (See table . 4.1).

4.16 Recruitment of parents

The 50 parents were purposely recruited from the three assessment centres, namely: University of Zambia (UNZA) Assessment Centre; Zambia Institute of Special Education (ZAMISE); and the University Teaching Hospital (UTH) Paediatric Child of Excellence Assessment Centre. Other parents were recruited from the public, grant-aided and community special schools and units.

For participants to know about this research study and join, I used different approaches. The first entry point was to first contact the coordinators of assessment centres. I phoned and sent letters or emails. (See Appendices D, E and F). ASD assessment coordinators had access to the names and details of parents in their database. Parents were first contacted by assessment coordinators who informed them regarding the research study. Later I had to contact them. All the parents were not coerced to join the research study and nor was there any possibility of them losing the services if they refused to be part of the study.

The second approach was to go back to the assessment centres and work with parents. This time I went to work at the University Teaching Hospital Paediatric Child Centre of Excellence (UTH) and the Developmental Intervention Clinic (DIC). This was before it was closed as it was an international donor funded project. I worked with two health professionals, one a paediatrician and the other a speech therapist. During this period, I was providing psychological therapy services to children with autism and their parents. After one or two sessions (sessions were conducted twice a month) of working with parent, I had to start the recruiting the participants.

The first step I took was to first leave the information sheet with the two health professionals to informally recruit participants. The two health workers were the ones that informed the parents about the study and shared the information sheets both in English and three local languages commonly used in Lusaka (Chinyanja, Chibemba and Chitonga). Parents were informally asked if they were willing to take part in the study. In addition, parents were requested by health workers to informally consent. The names of the participants who accepted to take part in the study were later given to me. I would again meet the parents and ask them if they were still willing to take part in the study and formally consented. Again here, the participants were not forced or coerced to join in the study. Participants who refused to join were not disadvantaged from accessing the services provided by DIC. (See 4.20 Informed consent, giving detailed information about informed consent).

To recruit participants in rural areas, I depended more on special education teachers who taught children with ASD in special schools or unit. Teachers would identify parents of children with autism, inform them and explain to parents about my study and later organise the parents in one place. Then my research team and I would set a date to visit the place. In some cases, I would request for a child profile file and any documents that showed that a child had autism. I would also check in the class register to check on the date of birth for the child, name of caregivers and date of entry into school. After meeting the parents, we explained the study again, read through the information sheet (Appendix J) again and later asked parents if they were ready to be part of the study. Even in this approach, no parent was coerced to join or was going to be disadvantaged in any way from our services or any other services if they refused to be part of the study. However, most of the parents were ready and happy to join the study because this was one of the first studies that actively involved them as affected group to find solution to challenges on access to ASD services.

4.16.1 Inclusion criteria for parents

This section explains the criteria used to select parents both from rural and urban settings. The following criteria were used:

Parents needed to be:

- Biological parents or step-parents and grand-parents, aunts and uncles or caregivers who had lived and cared for the child for two years and longer. The age range for the child was 2 to 14 years. This age range is a critical stage for a child's biological, physical, social-emotional and language development. It also covers the early years of education, which include early childhood education and primary schooling.
- Parents with a child diagnosed with ASD with the diagnosis done by qualified health practitioners.
- Parents or caregivers were to be 18 years and above. This is according to (Amendment) Act No. 2 of 2016, Article 266 of the Constitution, a child is anyone below the age of 18 (The Government of Republic of Zambia, 1996b) and in line with the United Nations Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child (Organisation of African Unity (OAU), 1999) which consider any person above the age of 18 to be an adult, one who is capable of being independent and to care for oneself and others.

- Parents of children with ASD must have lived in Zambia for not less than two years and spoke English or any familiar local language common in the Lusaka Province.

4.16.2 Exclusion criteria for parents

Parents were excluded from this study if they were not living with the child. No families were excluded based on socio-economic status, tribal or religion or education background (being literate or illiterate). In this study one parent had two children on the spectrum. Table 4.1 gives a summary of parents' biodata.

Table 4.1: Demographic description of parents.

The Age of Participants				
Age range	Male	Female	Final	
18-30	0	12	12	
31-40	1	9	10	
41-50	3	8	11	
51-60	3	4	7	
61-above	0	2	2	
Unknown	3	5	8	
	10	40	50	
Location where Participants Lived				
Rural	0	08	08	
Urban	10	32	42	
Never went to School	0	1	1	
Grade 1-7	1	14	15	
Grade 8-9	1	3	4	
Grade 10-12	03	10	13	
Higher Education	7	8	15	
Others	0	1	1	
N/A	0	1	1	
Marital Status				
Single	2	4	6	
Married	08	26	34	
Divorced	0	5	5	
On Separation	0	1	1	
Widows and widowers	0	2	2	
Others	0	2	2	
E	Employment Status			
	Formal	6	7	13

	Informal	4	17	21	
	Pieces of work	0	0	0	
	Not working	0	13	13	
	Others	0	3	3	
F	Number of children with ASD				
		41	10	51	
G	Number of children in school				
GRZ	Type of school	Public special school	18	5	23
		Public mainstream	0	1	1
		International School	2	0	2
		Private managed schools	3	1	
		Community Special school	4	2	6
		Grant-Aided special school	12	1	13
		Not in school	2	0	2
			41	10	51

* Note that one parent had two children with ASD. This makes the number of children 51.

4.17 Recruitment of professionals

All professionals were recruited from their respective working institutions. I either called, emailed, or visited the Heads of institutions at their offices to inquire about professionals that work directly with children with ASD (See Appendices F and G). Professionals were recruited from the following institutions:

- The Ministry of Education: School Administrators (Head teachers/Managers), special teachers in Special Education schools, Special Early Childhood Education Centres and Primary schools with special education units.
- The Ministry of Health: Health practitioners, pediatricians, occupational and speech therapists from both private and public health institutions.
- Ministry of Community Development and Social Services: Districts Social Welfare Officers and Senior Social Welfare Officers at the province and district.

- Quasi-government academic institutions: Education Psychologists and Psychiatrist. These were recruited from the University of Zambia and Zambia Institutes of Special Education.
- Quasi-government policy implementing institutions: Zambia Agency for Persons with Disabilities (ZAPD) and Teaching Council of Zambia (TCZ), Directors.

4.17.1 Inclusion criteria for professionals

Professionals were included in the study based on the following criteria:

- They must have been qualified in their respective field and must have had the experience of more than one year working with ASD children.
- They must have resided and worked in the Lusaka Province, but not necessarily be from a specific district.
- They must have been directly working with parents and children with ASD.
- Must have been a professional whose work was related to education, health, social welfare services and/or in policy which is related to ASD.

These professionals were targeted because studies have shown that most services regarding disabilities issues are provided by health, education, child welfare agencies and mental health centres (Humphrey, 2006).

4.17.2 Exclusion criteria for professionals

Professionals who had a child with ASD and were at the time providing direct support services to families of children with ASD participated as parents and not as service providers. This helped the researcher to have an in-depth understanding of the challenges of participants who were both professionals and parents. One professional who provided ASD services was included as a parent. Table 4.2 gives a summary of the professionals who participated in the study.

Table 4.2: Biographical data of professionals

		Male (06)	Female (17)
Location	Rural	1	0
	Urban	5	17
Employment	Government (Public sector)	1	12
	Private Sector	1	3
	Quasi-government Organisations	4	2
Occupation	Teachers/ school administrators	1	7
	Health workers	1	5
	Social workers	0	3
	Lecturers from colleges of education and university	2	2
	Policy makers	2	0
	1-5	3	6
	6-10	2	4
ASD training	11 and above	1	7
	Conference/workshop	3	5
	Part of academic qualifications	2	4
	Friends and relatives	0	0
	Certificates in ASD	1	4
	Others	1	4

4.18 Obtaining ethics clearance and informed consents

In each research, it is important to consider issues of ethics because it covers “our relationships with participants, with academic communities, and with the wider world in which we conduct research, as well as our research practice”(Clarke & Braum, 2013, p. 61).

In this study, I needed to protect the rights of the participants who could have been at risk of harm at any level of the study (Cresswell, 2014). Ethical clearance was needed for this study because I was dealing with parents of children with ASD, who are among the marginalised group, and who have been known to suffer high-stress levels (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016; Nyoni & Serpell, 2012; Turnbull, Turnbull, Erwin & Soodak, 2006), as compared to parents of children with other disabilities.

To be more conversant with ethical issues, I completed an online course on ethics with the National Institutes of Health of the United States of America (see Appendix S). I also attended training programmes on ethics with the University of Cape Town, Faculty of Health Sciences. The courses helped me to be more knowledgeable on issues of ethics related to qualitative research.

I obtained three ethical clearances. The first was the ethics approval from the University of Cape Town, Human Research Ethics Committee in the Faculty of Health Sciences (see Appendix A). Since the study was conducted in Zambia, I had to obtain an ethics clearance from ERES Converge, an agency of the Ministry of Health (see Appendix B). The third clearance was from the National Health Authority under the Ministry of Health (see Appendix C). I also followed the ethical regulations according to the World Medical Association Declaration of Helsinki Ethical Principles for Medical Research involving Human Subjects (Declaration of Helsinki World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects, 2013).

4.19 Informed consent

In each study, participants must be well informed about the study and are clear on the reason that they may need to participate. Participation should be voluntary as opposed to coerced. (Clarke & Braun, 2013). It was important to ask for consent from the participants in Phases one and two of the study. The reason was not to coerce the participants but to let them voluntarily participate in the study. I had to get informed consent from the participants who later signed the consent forms after reading the letter of information which talked about the study.

4.19.1 Informed consent from parents

The consent documents for parents were written in English and translated into three local languages of Chi Tonga, Chi Nyanja, and Ici Bemba. For parents who did not know how to read English, they were given the translated version in their respective local language. Participants who were not able to read or write had their consent form read to them by the research assistants

or I could read to them before signing or they could use an inked thumb to indicate their willingness to take part in the study. All parents had to sign a consent form in both Phases. In Phase one, parents had to sign a consent form (see Appendix K). Considering that Phase Two was longer, parents had to consent again (see Appendix L) to make a voluntary to continue participating in the study. To avoid raising their hopes and aspirations, I had to explain to participants that my role in the study was that of a facilitator and not an implementer of policies or projects. For the smooth running of the discussion, guidelines were developed on how each person was expected to conduct himself during the discussions and meetings (see Appendix I).

4.19.2 Informed consent from professionals

All professionals were given an English version of the information sheet (see Appendix M) which was left with them to read and understand before taking part in the interviews. Before conducting interviews, each professional was equally asked for their willingness to be interviewed in Phase one by consenting (see Appendices N).

4.20 Data collection tools

This section explains the tools used to collect and store data both in Phase one and two

4.3: Data collection tools

• RESEARCH QUESTIONS	• How do parents experience formal and informal services available in Zambia and what additional support services would they require and why? • What are professionals' experiences in providing formal support services to families of children with ASD, and what future support services would they desire families to access? • How does involvement in PAR support parents' empowerment to meet identified unmet needs of their children?
	
TOOLS FOR DATA COLLECTION	▪ Focus group interviews (Parents only) ▪ In-depth semi-structured interviews (Professionals only) ▪ Observation

	▪ Daily field notes ▪ Reflective learning and action learning ▪ Workshop ▪ Plenary sessions ▪ Audio, Video and Photos
	
STRATEGIES USED FOR DATA ANALYSIS	▪ Step one: Compiling data ▪ Step two: Disassembling data ▪ Step three: Reassembling the data ▪ Step four: Interpretation of the meaning of the data ▪ Step five: Conclusion
	
VERIFICATION OF THE AUTHENTICITY OF THE DATA	▪ Credibility ▪ Transferability ▪ Dependability ▪ Confirmability
	
DATA MANAGEMENT	▪ Description of risks and benefits ▪ Privacy and confidentiality ▪ Sensitivity to potential bias

4.20.1 How data was collected in Phase one

Data was collected through the triangulation of tools. These included focus group discussions (FGDs) with parents and semi-structured interviews with professionals. The reasons why I had to use FGD for parents and Semi-Structured Interview for professionals was to reduce on the costs and capture more data from both the parents and professionals. I avoided having one group of FGD which had both parents and professionals because most parents were found in one location, and it was easy to bring them together as a group considering that the number of parents with ASD was bigger than that of professionals in each location. Secondly, they were very few

professionals that work with ASD children. These professionals were found in various offices and working in different districts. It was going to be costly and a challenge to bringing together and conduct a FGD with them. In addition, maybe their voice was not going to be heard considering the large number of parents in each focus group discussion. Secondly, parents were not going to be free to express themselves and talk against the professionals in their presence. This might have affected their relationship and influence how future services were going to be provided by the same professionals they talked ill against. Again, I could not bring professionals together as most professionals had different professional career pathways which might not been so helpful to the discussion of parents. For example, having a FGD which had speech therapists and parents. In-depth interviews and FGD with professionals and parents greatly enriched the study.

In this study, I also used other instruments such as observation, reflective journals, and daily notes.

4.20.2 Focus group interviews (Parents only)

A focus group is a type of in-depth interview which is accomplished by a small group who are brought together by the researcher. Data is collected from “multiple participants at the same time” (Clarke & Braun, 2013, p. 108) and from “insiders or people in the know” (Fink, 2008, p. 270). Participants influence each other during the discussion and the moderator stimulates discussion with comments or probes. The questions that I used were relatively unstructured but were focused on the topic of discussion.



Figure 4-5: A photo depicting the researcher with participants during a focus group session. The photo is used with permission from the participants

In Phase one, nine FGDs with 50 parents were conducted. Seven FGD interviews were conducted in the Lusaka District and two were conducted in the rural districts of Chongwe and Chilanga. These interviews were conducted for three months. Interviews from both parents and professionals ran concurrently. For example, parents' FGD were conducted in the morning, and later in the afternoon I would interview professionals.

The transcribed data covered 110 pages double spaced and 670 minutes. The largest FGD group had 12 participants and the smallest had three members. Each interview lasted between 60 to 90 minutes. Table 4.3 shows the number of interviews conducted and how many participants were involved during each FGD.

Table 4.4: Phase 1 focus group discussions conducted

Number of focus group discussions (FGD) conducted	Number of males	Number of females	Geographical settings of the meeting	Total number of participants
FGD One	1	3	Lusaka Urban	4
FGD Two	0	3	Chongwe-Rural District	3
FGD Three	0	5	Chilanga Rural Area	5
FGD Four	2	4	Lusaka Urban District	6
FGD Five	1	2	Lusaka Urban District	3
FGD Six	1	4	Lusaka Urban District	5
FGD Seven	2	3	Lusaka Urban District	5
FGD Eight	1	11	Lusaka Urban District	12
FGD Nine	2	4	Lusaka Urban District	6
Total	10	40		50

The first FGD interview with three parents was conducted in the Chongwe-Rufunsa rural district. It was challenging to find parents with ASD children who met the recruitment criteria in the rural districts of Chongwe and Rufunsa. This was because ASD services hardly existed, and many parents might not have had enough information about ASD. I only managed to recruit three parents in Chongwe and I could not find any from Rufunsa. The second mini-FGD interview had three participants comprised of parents from the Lusaka District. Fourteen parents were invited to the meeting, but only three reported because of a heavy rains' downpour at the time. In both instances, I did not turn them away because I would have missed out on their rich information if I had sent them back without interviewing them. However, the data collected from the two mini-FGD was as rich as the one collected from the other FGDs, which had more than five participants.

To start the FGD, I introduced myself and the research team, then explained the objectives of the study. During the FGD, I used the interview schedule (refer to the interview schedule in Appendix O). Participants were asked about their expectations during the discussion and what

they understood by the term ‘ASD’ and support services. Icebreakers and triggers were used during the main discussion. Probing was further employed with some prompts and humour (Coolican, 2013; Rossman & Marshall, 2011). Parents were encouraged to express their feelings and perceptions about the topic and to freely interact with one another. The merits of the focus group discussion are that participants can air their problems, interact with each other, and bring new insights into the group regarding the topic (Flick, 2018). The major challenge during FGD were issue of confidentiality. It was difficult to guarantee participants total confidentiality during focus group discussions. However, parents were asked to sign an agreement form on issues of confidentiality and the respect of other people’s opinions.

4.20.3 In-depth semi-structured interviews (professionals only)

Semi-structured interviews (SSI) are designed to elicit some responses from the participants regarding a phenomenon they experienced (McIntosh & Morse, 2015). I used semi-structured interview guides (see Appendix Q) with the 23 professionals who came from health, education, social services, universities, and government agency institutions. Individual semi-structured interviews enabled the interviewer manage participants to be focused on the topic of discussion and answer the research questions (Corbin & Strauss, 2015) accordingly. I frequently had to seek clarity from the participants regarding the meaning of their comments.

4.20.4 Observation

Observation is one tool that was used continually in this study as I observed the evolving of dynamic situations (Fink, 2008). Observation of participants during the study is critical as it enables the researcher to make meaning of the participants’ activities and behaviours (Patton, 2015). The observation of participants was an ongoing activity from the time participants joined the study up to the end of activities in Phase two. I did not isolate myself during the observations. I interacted with participants. All observations from the participants, my reflections and those observations made by research assistants, and I were recorded in notebooks. The notes were used as part of my reflection journaling (See chapter eight for my reflection).

I also used Journaling as another data collection tool. Since most of the activities were video recorded, I had to review the videos and observe participants’ emotional reactions which I could compare with my notes. Even in the videos, I was also able to have a critical observation of the participants, actions, voices, behaviours and participation in activities.

4.20.5 Daily field notes

These are aid-memoirs of short notes which assisted the researcher in later reflection (Gray, 2014). During the research period, field notes were used to write down in a diary important activity observed. The field notebook was also used to keep the contact numbers, dates of appointments and schedule or rescheduling of meetings. All the activities which were recorded helped me in my reflective journaling, and that led to a new understanding of the phenomenon (Spalding & Wilson, 2002). It also assisted me to verify the rigour of qualitative research (Lincoln & Guba, 1985). Journal reflections were not fixed, but interwoven with questions and stories from the field, and provided a deep reflection on what it meant to be a parent of a child with ASD, and the barriers faced in accessing ASD support services.

4.20.6 Reflective learning and action learning

In this study, I used both reflective learning and action learning meetings because they were “indissolubly united” (Baum et al., 2006) and illuminated each other during activities. Reflective learning was used in this study because it allowed participants to think of how activities were conducted, relate the lessons learned to their own experiences and make meaning of the activities conducted. Parents had to practice reflective learning by expressing their challenges through drawings pictures of their lived experiences. Parents were also involved in writing and reciting poems. Play and re-playing video clips and photos of previous activities formed part of participants’ reflective learning process.

Action learning was an appropriate tool because participants became aware of their motives and actions and accepted their learning as part of their personal growth (McGill & Beaty, 1995). This showed that action learning in disability studies is critical as it enabled participants to be self-motivated and fight for social change in their communities. It also provided a platform for parents to act and learn from other fellow parents and experts who had similar experiences. This further motivated parent to desire for something better for themselves and the child with ASD.

4.21 Phase two

Phase two was further divided into several stages as follows:

4.21.1 Selection of participants

The second phase of the study involved 17 parents (three males and 14 females). These parents volunteered to participate in the study for ten months. Together with my two research assistants, we had to come up with some categories on how to capture a diverse group of parents that would make it a balanced group of participants. The 17 parents formed a parent-led support group that

had both parents from rural and urban areas. (See chapter six on how the group was formed and the role they played in the study). To check on participants' willingness to continue with the study, a register was provided which each participant had to sign during the meetings (see Appendix R).

4.21.2 Data collection tools

In Phase two, data was generated using various tools. These included workshops, plenary sessions, observations, journal reflections and field notes. The tools were interlinked in all the phases.

4.21.3 Workshop

Workshops were organised by the participants who saw the need to get trained or train others on issues that needed attitude and belief change (Montgomery et al., 2016). Various strategies were used in the workshop to elicit information, which included plenary sessions, group work, debates, and group discussions. During the workshop, my concern was not on the methods used, but rather on the action taken to promote behaviour change (Chambers, 1994). Parents and professionals collaborated and established a partnership on how to educate the child both at home and at school. Workshops are different from focus group discussions because they have specific learning objectives that needed to be achieved at the end of the workshop. During workshops, parents were invited to a workshop (See appendix H). As the workshop was going on, I managed to collect a large amount of data within a short time. Additionally, participants networked as they learned new skills within a short period of time.

The major challenge of conducting a workshop was to get participants together, mostly those who were in formal employment. This involved phoning, writing letters, and emailing people to confirm their participation. Workshops are costly because they involve organising a venue that is appropriate for large meetings. Apart from that, there were many other costly logistics involved, such as buying stationery and refreshments, transport costs and paying the facilitators. See figure 4.6 of a parent debriefing others during the workshop plenary session.



Figure 4.6: Parents' brainstorming activities

(Adapted with permission from the participant)

4.21.4 Plenary sessions

A plenary session is a session of a conference in which all members of all parties attend by coming together (Cohen et al., 2007). In keeping with the principles of plenary sessions, a chairperson would be chosen to facilitate the activities. In cases where I was facilitating, I would ensure that participants kept minutes during the introduction and the presentation. I had to also set ground rules on how to run the sessions. For example, all speakers had to speak through the chairperson, phones on silent respect for each participant. We used charts, power points and group meetings during the activities. They are challenges in the use of plenary sessions. One of the challenges is that organising participants require enough time. Managing the audience may be a challenge during presentations. To overcome such challenges, I got support from two research assistants who helped me organise the activities.

4.21.5 Other instruments used to collect data in Phase two

Apart from the above instruments, I also used observation, journaling, group discussions and interview guides (see Appendix P).

To capture more data and avoid losing data by only writing, I equally used the following electronic devices:

4.22 Audio, video, and photos

Audios, videos, and photos are tools that are used to capture data for validation. Audio recordings were used in both phases. Before using them, I had to get consent from the participants to record, take pictures, and use some photos in my thesis report. Three audio recorders were used for recording. This gave me time to allow the interviews to flow without interrupting the participants, whilst taking notes during the interviews. The merit of using audio recordings was that I was able to play and re-play them during the transcription process. Data could be collected within a short time. The use of audio meant that I was able to collect data that was too complex to comprehend whilst writing, observing the behaviour, and listening to the discussion (Flick, 2006). The information captured by the video was non-selective as it captured all the activities which the audio could not. I had to obtain consent to use the video. Most of the time the video equipment was stationed at a distance from the participants to reduce nervousness and tension. I did not have challenges in using recording devices as I had used them before in several prior research projects. However, we faced some technical challenges in recording the full presentation of the workshops. The audio recordings were not clear enough. This became a challenge when participants were divided in groups. This meant that some groups had no audio recording devices. Secondly, the hall was big, and we did not have the public address system to use. This made the recording not clear enough as the hall was big. However, the research assistants and the facilitators kept field notes that assisted us to capture important points.

4.23 Data analysis

In qualitative research, the goal of data analysis is for the researcher to demonstrate how precise, consistent, vigorous and exhaustive the data is (Cresswell, 2007; Miles et al., 2020). I drew most of the data analysis skills from the book entitled “*Qualitative Data Analysis. A Methods Source Book*” (Miles, Huberman, & Saldana, 2020), where I learned how data is analysed qualitatively. I also attended workshops and seminars on data analysis, which was organised by the Univesity of Cape Town Library and the Faculty of Health.

I was hesitant to use the term ‘data analysis’ in this study because the process of data collection was an ongoing process that was interlinked and intertwined. Therefore, it becomes a challenge to analyse with tools that have a back-and-forth approach to data collection. I opted to use the term ‘data condensation’ as described by Miles, Huberman and Saldana (2020) who defined it as “the process of selecting, focusing, simplifying, abstracting and/or transforming the data that appear in the full corpus (body) of written-up field notes, interviews, transcripts, documents and

other empirical materials.” (p. 8). The merits of data condensation are that the researcher can organise and sort the data for easy description and verification.

As a qualitative researcher, I had to use creative skills to interpret participants’ social behaviours within a real-world situation (Flick, 2014; Strauss & Corbin, 1989). states that:

Qualitative data analysis is the interpretation and classification of the linguistic (or visuals) material with the following aims: to make a statement about the implicit and explicit dimensions and structures of meaning and making in the material and is represented in it (Flick, 2018, p. 420).

In this study, the data collected in Phase one was analysed separately from Phase two. Phase One data was the first to be analysed. This was because the findings in Phase one formed the basis in Phase two to identify and priotise some barriers parents experienced in accessing the services. However, data processing was an ongoing activity throughout the study.

In this study, data was analysed using the five steps. I employed Yin’s (2016) process which included the following steps to analyse the data: (1) compiling; (2) disassembling; (3) reassembling; (4) interpreting the meaning; and (5) conclusion. This approach was selected and was more appropriate for this study because it is easy to follow, and it has simple steps on how data can be analysed at each stage of data collection. For example, during data collection, in step one, data was compiled to develop groupings. In step two, data was disassembled to reduce and eliminate themes that were not much related to the phenomenon. In step three, data was reassembled to cluster core themes. For step four, I checked the patterns against the transcriptions of the interviews and used my journal reflexivity to help me interpret the meaning of the data. Step 5 gives a summary of the description of the participants’ experiences. Such steps are easy for qualitative researcher to use. I now give a full detailed step-by-step description of how data was condensed.

4.23.1 Step one: Compiling data

The first approach to data condensation was to compile all the data collected and store. The compiled and stored data include interviews, document analysis, and field notes. These were stored into folders and files. Audio and video recordings that were compiled were filed according to the dates on which the interviews were conducted for easy identification. Literature shows that “orderly data leads to stronger analysis and ultimately to more rigorous qualitative research” (Yin, 2016, p. 190). Later, recordings were exported into an Express Dictate Digital computer

software V5.95 for transcription. The use of 'Express Transcribe' enabled me to listen attentively to the recordings at a slow or fast pace. I could rewind the audios, whilst typing the scripts into words. This process is labour intensive and challenging. It took several months to transcribe the data as the process was time-consuming (Creswell, 2007) as it involved going back and forth, reading and re-reading through the scripts. This process was important because I was becoming familiar with the data during transcription (Clarke & Braun, 2013). It also assists me to approach the data analysis with critical thinking and a reflective approach.

To have a second opinion on how the data was being analysed, two transcribers were hired to transcribe six interviews. After transcription, I had to go through them again, listening to the recordings and making corrections to ensure accuracy.

To maintain the original rich meaning of some phrases, some local words were left in their original language to avoid losing their original meanings, but they were also parenthetically translated into English for readers to understand their meanings.

4.23.2 Step two: Disassembling data

Disassembling is the first level of open coding. Coding is defined as "the process of identifying aspects of the data that relate to your research question" (Clarke & Braun, 2013, p. 206). The first step was to familiarise myself with the dataset. I used the NVIVO software to develop themes and sub-themes. I had to highlight the text in the computer software to read words analytically and actively, to make meaning of the data, organise the text data, select words and terms, code the text and get the hidden meaning of the stories, manipulate the texts, and display the codes. Most of the words in the first coding consisted of longer sentences (Flick, 2018; Miles Huberman & Saldana, 2020). During this phase, attention was paid to the frequency of some descriptions and their correspondence with other entries. Data was further analysed by paying attention to the content and language used to make generalised statements of what participants said and meant.

4.23.3 Step three: Reassembling the data

Step three of data analysis involved inductive and deductive reasoning. Themes, sub-themes, and categories were developed by combining and refining the codes developed in stage 2. The themes changed several times to match with realities that emerged from the categories, and which were in line with the research objectives. Furthermore, I had to find appropriate themes that were "evocative, catchy, concise and informative" (Clarke & Braun, 2013, p. 258) (see chapter five).

4.23.4 Step four: Interpretation of the meaning of the data

In qualitative research, the core activity is to interpret the data for understanding or explanation in a language that can well be understood by the readers. In this study, data interpretation was an ongoing process. It was during this stage that on several occasions I had to reflect on the data completeness by checking whether the analysed data had the beginning, middle or the end of data interpretation. It was at this stage that I also wanted to observe whether the data being analysed was generating new knowledge that was going to be credible to peers in the same field of ASD, and they would accept its interpretation. Chapter seven gives more details on how data was interpreted.

4.23.5 Step five: Conclusion

The last stage of data condensation was the conclusion which was based on the lessons learned from the study findings and the benefit of this study to the readers. In the conclusion of the data analysis, I proposed recommendations and limitations and gaps in the study for future consideration by other scholars (see chapter eight). In this study, data analysis was used as an iterative process where I would move backwards and forwards. This meant that the conclusion of my earlier analysis could influence the collection of further data.

4.24 Verification of the authenticity of the data

This section discusses the verification of the data collected by looking at its credibility, transferability, **dependability, and conformability.**

4.24.1 Credibility

Credibility is understanding the context of the data collected and establishing that the findings are true. For a research study to be accepted by other readers, experts in the field of study must scrutinise the research study (Shenton, 2004). In a qualitative research study, ensuring credibility is very important as it establishes the trustworthiness of the study (Lincoln & Guba, 1985; Thomas & Magilvy, 2011) and the confidence placed in the truth of the research findings (Macnee & McCabe, 2008). Studies revealed that research credibility allow researchers to recognise their own experiences in the study and present an accurate description and interpretation of the participants' experiences (Anney, 2014; Morrow, 2005; Thomas & Magilvy, 2011).

To achieve credibility, several approaches were used, which included observation and the use of reflective journals, followed by reflection. Questions were asked such as: "What is it that you plan?" and "Who is going to be responsible?" Together with the parents, we had a ten-month

prolonged engagement. During this period, parents' voices were heard and respected in the findings (Guba & Lincoln, 1994). Data triangulation or informants' triangulation was done. Interviews, focus group discussions, observation, and document analysis were used to validate the data and reduce bias during the period of data collection (Shenton, 2004). To promote transparency, parents were able to make comments, suggestions, and approve or disapprove of some of the comments. Participants were involved in identifying the problem affecting them, planning an action programme, and implementing it.

4.24.2 Transferability

Lincoln and Guba (1985, p. 290) define transferability as "the ability to transfer research findings from one group to another, or how one determines the extent to which the findings of an inquiry have applicability in other contexts or with other participants." In this study, research transferability was achieved through a detailed description of the process of how the data was collected. This included how a researcher became part of an instrument during data collection, the instruments used for data collection and analysis, themes, sub-themes, and categories that emerged. The study provided details of the locations where data was collected, the length, and procedures of data collection, the number of participants involved, stages of data collection and ethics clearance. Guba (1981, p. 86) explains that "descriptive data allows comparison of this context to other possible contexts." The description allows other researchers to see how they can conduct a similar research project by using a similar approach. However, I may need to caution the readers that the themes and conclusions might not apply to parents who live in remoter parts of Zambia or other countries because of their cultural, geographical, and social-economic status and understanding of ASD.

4.24.3 Dependability

Shenton (2004) postulates that for any research to be dependable, the methods used must be consistent with how the study was conducted with respect to time and data analysis procedures. To achieve dependability, a researcher needs to keep an audit trail of how the research was conducted. This allows the readers to evaluate how decisions were made. It also provides the consistency and accuracy of the study. In this study, the audit trail was tracked by describing the type of tools used to collect and store data. The tools used were audio and video, journaling, and field notes, interviews, plenary sessions, and workshops. I have given a detailed account of the aims and objectives of the study, sample population criteria, how data was collected, the instruments used, the time frame of data collection and how data was transcribed, interpreted, and analysed. I have further described how interviews were conducted using prompts, and probes

to encourage and obtain data from participants. In addition, the appendices of all the instruments, memos and other documents that were published during the study have been explained in this study. A trail has been left showing the methodology used, its merits and demerits. This detailed approach is vital for future researchers to repeat similar studies as a prototype model.

4.24.4 Confirmability

Confirmability is described as the degree to which the results of an inquiry could be confirmed or collaborated by other researchers (Baxter & Eyles, 1997). In this study, an audit trail is provided for readers to judge and make decisions on how the study was conducted. The coding was cross-checked by the research assistants and the two research supervisors. Some of the interviews were transcribed by independent individuals whom I hired for more credibility. I have provided the data analysis process and a detailed description of how the data was collected at each phase, and how it was easily tracked. This is supported by the timeline which was drawn and shown in all the phases on how the research was conducted. Each reader can revert to the origins of the study.

4.24.5 Data management

To keep track of the interviews, each recorded interview was given a confidential unique number and put in a specific folder in my password-protected computer (Flick, 2014). Materials were locked in my office cabinet during and after each activity. This promoted adherence to confidentiality and the privacy of the participants' details and information. All audio and video materials were stored in my computer and locked. This was after labelling all the folders and files. The labelling showed the data when the interview was done and its location, and had a specific number assigned to it.

4.24.6 Description of risks and benefits

Participants were informed that participation in the study was voluntary. This helped participants to psychologically prepare for the study and understand some of the economic losses that might come with their participation. Participants would suffer economic loss because the time which they needed to be productive and do their work would, instead, be used to participate in the research study. We did not experience any risks or accidents during the data collection. At the end of the project, parents who completed all the Phases were given a food basket hamper K250 (\$25 USA dollar) as a token of appreciation. To further mitigate the economic risk, transport refunds and refreshments were provided at each meeting we had together.

4.24.7 Privacy and confidentiality

To maintain further group confidentiality, each participant was required to agree to a code of rules that were introduced to them at the start of the study. However, it was difficult to achieve total confidentiality, considering that we were working as a group. Participants were informed that, ethically, the researcher was mandated to disclose some information to a third person if there was evidence of child neglect, abuse of persons with disability, sexual abuse, family violence, and non-caring attitude for a person with notable diseases such as tuberculosis.

To use the photos and recordings in the thesis and during the data collection the parents had to consent. Pseudonyms were used in selected photos or recorded videos and audios during the research write-up. No names were used in the photos used in the thesis.

4.25 Sensitivity to potential bias

In qualitative research, a researcher constructs reality through the lenses of the participants, and this can be achieved by interacting with the participants (Merriam,2009). Strauss & Corbin (1989) observed that it is a challenge for a researcher to completely disassociate one self from the participants. To avoid potential bias, I had to frequently consult the participants each time we had an activity. In addition, I could also consult my supervisors and research assistants. I also kept a field note guide to help me focus my thoughts on the topic. Despite that, I knew the cultural dynamism of the parents, both rural and urban, since I have lived and worked in both rural and urban settings. I was sensitive to their needs. I also informed the parents that I was also a parent of a child with ASD who wanted to have more insight into what it means to be a parent of a child with ASD. This helped in earning their trust.

4.26 Summary of the chapter

Chapter four covered the methodology and method used during the study. Qualitative participatory action research was selected as an appropriate methodology because of its democratic characteristics whereby affected participants actively got involved in issues affecting them. The chapter explored how we entered the community to select the participants. The sampling methods, sample size and sites were discussed. The chapter had two phases: Phase one had 73 participants - both parents and professionals - who discussed their experiences with autism. Phase two shows how 17 parents were recruited to participate in addressing the barriers and hindrances to autism services. The chapter has also highlighted the tools used to collect data, which included focus group discussions, interviews, field trips, participant observations and other storage devices such as audio and video equipment. Chapter four has explained how data was

collected and analysed, research validity and ethical considerations. The next chapter discusses the first part of the findings.

CHAPTER FIVE

IDENTIFYING THE STATE OF THE PROBLEM: THE FINDINGS- PART ONE



Figure5.1 : Eagles face many barriers in rearing their young

Courtesy of our first son Siabong'a Katisha Nyoni

Just as eagles face many barriers in protecting their young, so do parents of children with ASD face challenges in accessing support services for their children, as revealed by the quote below:

I took my grandchild for baptism. The church was shocked that he was amongst the babies. The priest asked me why I wanted to have a big child get baptised as if he was a baby. I told him [priest]: "Ask the child his name and his age. If he answers you, don't baptise him." (Parent: FGD8 P6).

5.0 Overview

Chapter five and six discuss the findings based on Phase one and two respectively. The study had a two-phase process. Phase one focused on an inquiry into the nature of problems that parents had faced in accessing ASD services (chapter five), whilst Phase two discussed the action taken by parents to address the barriers to ASD services (see chapter six). The goal of Phase one was to explore parents and professionals' experiences with formal and informal ASD services.

Chapter five explores the experiences of parents and professionals with current ASD services and specifically identifies opportunities, barriers, and hindrances to available ASD support services. The research questions that guided this chapter were as follows:

- What are the parents' experiences of the formal and informal support services available in Zambia?
- What are the professionals' experiences in providing formal support services to families of children with ASD?

Using semi-structured interview guides, data was gathered from professionals using in-depth interviews, and from parents via focus group discussions. Chapter five discusses the findings based on the themes generated from the interviews conducted with parents and professionals. The three themes, eight sub-themes and many categories were generated. The themes generated are juggling multiple sources of ASD knowledge, community and informal support, ASD specific knowledge and formal service.

In this chapter, only relevant excerpts were extracted from the experiences of parents and professionals. These excerpts provided a rich, in-depth description of the prevailing available ASD support services in Zambia. To avoid losing the context, cultural and original meaning of the words, quotes were maintained their original local language phrases. The words in local languages are highlighted in bold text and have been translated into English for easy understanding by the readers. Quotes from parents and professionals

Table 5.1: Participants' identifiers

Category	Identifier	Participant
Professionals	LPEDU1 PP2	Education sector professionals
	LPHLT1 PP20	Health professional
	PP14	University professional
	LPSW1 PP12.	Professionals from Social Welfare Services.
	LPM1 PP9	Professionals as Policy Implementers
Parents	Parent: FGD9 P5	Categories of parents.

In chapter five, three themes were generated that are linked to the data collected in Phase one. The three themes are depicted in figure 5-2 below:

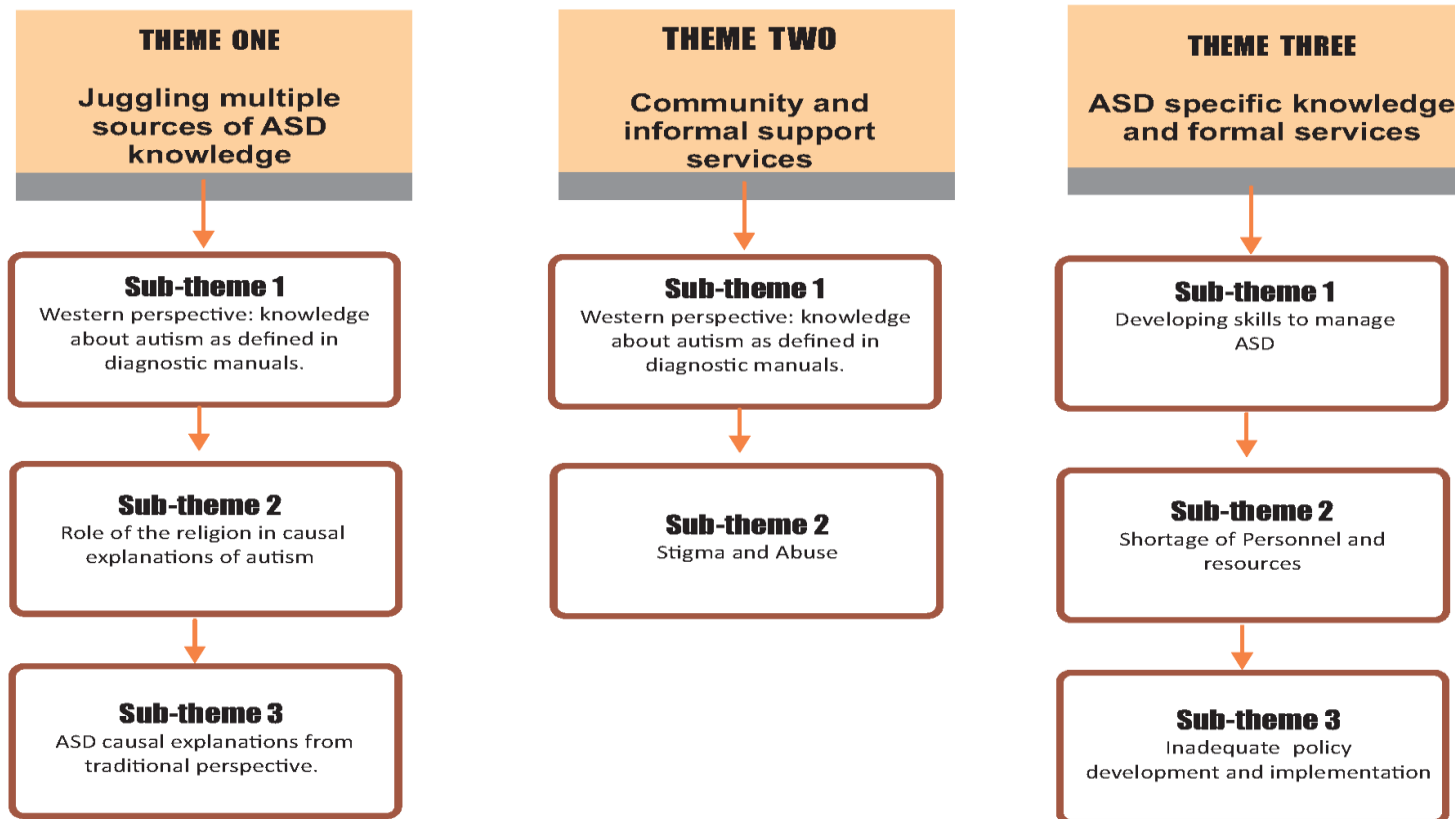


Figure5.2 : Phase 1 themes, sub-themes and categories

5.1 Theme 1: Juggling multiple sources of ASD knowledge

Theme 1 was related to knowledge of ASD condition from the Western medical perspectives, knowledge of the ASD condition from African Traditional healers' beliefs and knowledge of ASD condition from religious beliefs (see Table 5.2). The theme highlighted the desire of parents and professionals to have a society that was well informed and knowledgeable about ASD support services, and which strove to be aware and sensitive towards children with ASD and their families. Table 5.2 shows the themes, sub-themes and categories that emerged.

Table 5.2: Structure of theme 1 including sub-themes, and categories

Theme	Sub-theme	Categories
Theme 1 Juggling multiple sources of ASD knowledge	Sub-Theme 1: Western perspective: knowledge about autism as defined in diagnostic manuals.	▪ Meaning vs definition of ASD ▪ Behaviours associated with ASD as a condition. ▪ Insufficient understanding of ASD
	Sub-theme 2: Role of the religion in causal explanations of autism.	▪ Parents negative experience with religion ▪ Discriminatory views that religious leaders have toward children with ASD (from the parents' perspective)
	Sub-theme 3: ASD causal explanations from traditional perspective.	▪ Culturally rooted beliefs about the causes of disabilities ▪ Community sympathy

5.1.1 Sub-theme 1: Western perspective: Knowledge about autism as defined in diagnostic manuals.

Sub-theme 1 is based on the lived experiences of parents and professionals, and their limited understanding of the causes, diagnosis, treatment, and management of ASD according to the diagnostic manuals. The stories from the parents and professionals are interlinked and highlight how challenging it was to explain ASD from a Western medical perspective.

5.1.2 Meaning vs definition of ASD

The term ‘ASD’ was a relatively new term for the masses in Zambia. This is evidenced by the lack of a term in the local languages. Parents had a challenge in understanding the meaning of the term ‘ASD’ and heard of this health condition for the first time when their children were in the assessment phase. The inability to comprehend its meaning resulted in the failure of parents to explicitly explain to community members what ASD was, including its causes and treatment. When asked, “What does the term autism mean to you as parents?” several parents had this to say:

For me it's...It's aaah... people who see things differently from the way we see them, and they see them in different variations and intensity, depending on how you are affected. That is what it means to me. (Parents: FGD5 P1).

It is part of the new terminologies [ASD] I heard after being told that our child is autistic. It's one of these new terms. We haven't done any work, to go very much into it, but because that is how they define it. Of course, yes, they say autism, but I don't put it much on the side. To me, autism is a passing word. I still believe it's just one of those conditions. (Parents: FGD5 P2).

For me, the way I know it is that they are children whose brain is confused and damaged and they were not born normal. These are children who do things anyhow, and they can sit anywhere and do anything. (Parent: FGD4 P7).

These quotes illustrate the challenges of parents in comprehending the meaning of the term ‘ASD’. Parents could only partially describe ASD characteristics from the Western medical perspective, as was informed by the professionals during diagnosis or from other sources such as radio and television or the internet.

5.1.3 Behaviours associated with ASD as a condition

The stressful journey of being exposed to ASD began when parents noticed the child's atypical behaviours during the early childhood developmental stages. Parents had a vague idea of the child's condition and did not associate the child's atypical behaviours with ASD for years: *We never knew autism until he was six. We thought it was just a speech problem. He started talking, I think when he was 7 years old.... You know when you are ignorant about something* (Parent: FGD9 P5).

In Zambia, many people were not aware of the medical treatment and diagnosis of ASD. The limited ASD knowledge was common among parents regardless of their social-economic and education status as observed by professionals: *I see that even well-educated parents, they are there, still don't understand their child has autism.* (Professional: LPEDU1 PP2).

ASD was hardly known in Zambia because of a lack of awareness and access to resources of information. The people who were aware of it and who had ASD knowledge were mostly families that had a child with ASD. A father narrated:

My take on that is I am thinking, in Zambia, not everybody knows about Autism. For those of us who know autism, it's because we have a child, a nephew or niece of that nature and we are all learning about it. (Parent: FGD7 P3).

The quote above revealed that few people were informed about ASD. Parents observed that the community had limited knowledge about ASD, and they associated ASD with madness or mental illness: *Some people who do not know about autism, say that the child is not normal.* (Parent: FGD4 P5). The term 'not normal' means that the child is mad and was a burden to the community.

Stories of limited ASD understanding, and its meaning were equally common amongst professionals, who found it both difficult and frustrating to define ASD in the Zambian local languages. A health professional acknowledged the difficulty she faced in defining ASD in the local languages. She narrated:

... But it's not easy because just trying to explain what autism is in Ci Nyanja or even in Ici Bemba. But we try. Yes, even though they don't understand what autism is, but I think at the end of the day they go back, knowing that my child has autism. (Professional: LPHLT1 PP20).

Parents expected health professionals to be aware and more knowledgeable about ASD, considering that their curriculum on health issues was based on Western education. When parents were asked to share their thoughts on how knowledgeable health professionals were about ASD, most parents responded in the negative: *They normally don't know about ASD and the problem the child is facing.* (Parents: FGD2 P3).

The encounters that parents had with professionals were stressful and emotionally draining because it could take parents a while to educate and explain to health professionals what ASD was. One parent had this observation when she took the child to the hospital:

Last month, I took my child to the hospital; I took it for granted that since they were medical personnel, they all know about ASD, but to my surprise, I had to start explaining. (Parent: FGD8 P10).

The limited understanding of ASD by health professionals resulted in “fights” with parents every time they took the child for other health services. A mother recalled:

We have had fights with the doctors as well. They don't seem to know what autism is and you would expect professionals to know better, but they don't know until you explain to them. (Parents: FGD5 P3).

The “fights” continued between parents and health professionals who used wrong terms such as ‘mental retardation’ to describe ASD. The term ‘mental retardation’ enraged parents. A mother narrated:

A paediatrician, in-charge of the entire hospital said that my child was mentally retarded, and we said what did you say? My child is retarded? What did you say? The paediatrician then said; Ohoooo.... Nooooo....Then I told her that my son is autistic not retarded. (Parent: FGD5 P3).

Furthermore, parents reported that clinicians who had some knowledge about ASD were more theoretical than practical as they wanted to use their acquired theoretical knowledge to treat all disabilities including ASD as the same:

....with professionals, I came to understand especially the medical personnel, they are more theoretical. In as much as they may understand this is a spectrum and

it affects these children differently; they want to apply everything that they know to your child. (Parent: FGD5 P1).

Health professionals who had little or no experience working with ASD cases were shocked when confronted with an ASD child's atypical behaviours, which they associated with poor parenting styles. A grandmother vividly recalls her experiences:

We took the child for malaria testing. It was a challenge and the child started crying. They were all surprised that such a big boy would cry with a malaria jab. It was worse when they needed to give him an injection, they had to call the security guard to come and assist in holding him. The nurses don't know it. I had to write in the book that the child is special. They were surprised by the word special child. They started asking themselves, "How special is the child?" (Parent: FGD8 P6).

When you take him to the hospital, the child cannot stay in one place for a long time and the people will be shocked by the child's behaviour considering his age. You find that at times you must lift the child, old as he or she is. The nurses will just be looking at you until you gather your courage and explain the child's problem to them. (Parent: FGD9 p4).

The term "special child" in this context meant that a child had an ASD condition, and required urgent attention because of hyperactive behaviour. However, professionals mistakenly linked the term "special child" to that of a prominent person in society, rather than to the disability itself. The limited awareness and knowledge about ASD by health professionals could be attributed to a lack of educational resources about ASD in higher learning institutions such as the University of Zambia. The health educational curriculum had limited content on ASD diagnosis and treatment. A private health consultant had this to say:

The training that we do as doctors, you just get attached to the unit and that unit may have some children that are autistic, but outside of that, there is no regular training where you can say you need to learn more about the diagnosis of autism. (Professionals: LPHLT1 PP16).

Parents discovered that even teachers and schools were not aware of ASD and that there was a need to promote ASD awareness in schools: *Schools should be made aware about autism...* (Parent: FGD5 P2). Another parent added: *Some teachers don't pay much attention to children*

with autism because this is a new thing; there is no awareness of the services available. (Parent: FGD6 P5). The lack of ASD knowledge by teachers could be attributed to limited content about ASD in the College of Education, Early Childhood Education, Primary and Secondary curricula which hardly addressed issues of ASD.

Professionals acknowledged some gaps among some teachers mostly those who had limited experience: One professional said: *Well... gaps are there. Gaps in terms of teachers. Some trained teachers have no hands -on experience. Most of the teachers are there, but they have no hands-on experience with ASD.* (Professionals: LPUN1 PP15).

Professionals also observed that even parents themselves who normally blame professionals. This has resulted in parents accusing all professionals as having limited knowledge about ASD. Some professionals felt the first task that professionals have to do when dealing with parents of children with ASD is make parents knowledgeable and understand what ASD is. This was the observation by one professional who said:

Well, the mainly thing that we came across is the lack of awareness of the child's condition. So, they do not know whether it is autism, mental retardation, whether it is other abnormalities in the brain, intellectual deficits. So, by not knowing that, they do not know what expectation to have. So, my first role, my first job when I talk to a parent, I tell them what is autism? What are the signs and symptoms? Behaviour manifestation. What is the cause and what are the problems (Professionals: LPUN1 PP14).

In addition, professionals observed that many parents felt teachers had no knowledge about ASD because they obtained most information from mainstream teachers who have no training in special education as compared to special early child education schools who were trained. One professional narrated:

I know of a few schools where parents can seek some help. We have UTH special school. There the staff, are trained to look after these children, to help them learn some scholastic skills and life skills and in fact UTH is directly attached to Lorena special school in the UK. (Professionals: LPUN1 PP14).

Knowledge of ASD services from a Western medical perspective (sub-theme 1) did highlight the limited understanding of ASD by parents, professionals, and the community as they

searched for services from the Western medical perspective. The limited understanding of ASD was because ‘ASD’ as a condition was a relatively new disability and the understanding of its causes, diagnosis and treatment from a medical perspective was still a challenge to parents, even among professionals such as special education teachers and clinicians who had had Western education training on ASD. Sub-theme 2 highlights the participants’ knowledge of ASD services from a religious belief perspective.

5.2 Sub-theme 2: Role of the religion in causal explanations of autism

In sub-theme 2, participants narrated how ASD services were linked to religious beliefs, and how they found religious services to be discriminatory and unsupportive to both the child and parents themselves.

5.2.1 Parents’ negative experience with religion

Zambia is a Christian nation, as enshrined in the Zambian constitution. Many Zambians are practising Christians with a few belongings to other faiths (Islam, Hindu, and African Traditional Religion). Religious organisations provide emotional, social, and spiritual healing, and attending worship is a very important part of life for the Zambian people. Nevertheless, parents of children with ASD as practising Christians found themselves in ‘fights’ with church leadership and the Christian community in trying to dispel the religious myth that an ASD condition was caused by demonic powers and parents’ little faith in the healing power of God. One parent narrated:

This is what I tell people that this is not demonic, because, if it was a demon, it would have had gone. I know I need to calm him down. I know where this thing is going. They think oh no, “you have to go and see this prophet”. I tell them I also know how to pray; I also believe in God, and I know this is not demonic. He is just different. (Parent: FGD5 P3).

The above statement illustrates that the church understood ASD as a supernatural condition, and the only cure was through prayers to cast out demonic powers which afflicted the child. Consequently, the only support that the church members could offer parents was to cast out demons from the child. Parents had to consistently reject healing services that were offered by church members to cast out demons from the child with ASD. This was because at times it was traumatising to the child who could not withstand the shouting whilst prayers were being said and it was depressing to the parents, who were regarded as people of little faith.

One father, an engineer by profession, reflected on his spiritual journey as he searched for church support.

He narrated:

So, when it comes to churches. As for me, in the past five years which we have been going there. I think I feel I reached the position of a pastor in my house because everywhere we go somebody wants to lay hands on our child. So, I say no, no. I have laid my hands, I prayed. I have fasted and I know my spiritual position. (Parent: FGD5 P2).

This parent's experience showed church members and clergy related ASD to demonic powers that needed curing and parent came to accept that the cause and treatment of ASD had no relation to demonic powers. However, the community was willing to assist and see parents live a normal life but did not know how to help but pray for the child. Parents who wanted to attend worship with their children were also denied an opportunity to congregate with other believers because the church leadership could not understand and accept the child's atypical behavioural condition. A mother recounted her story:

I used to take my child to church. When people start shouting during prayer sessions, he could imitate them and shout louder than all church members. The whole church would be surprised and look at us. One church member told me to take the child outside. When I went outside, another member asked me why I was not inside the church. I told him that I was told to be outside because my child was making noise in the church. She also said: "Don't bring such children to church". That is how I went home. I stopped going to church. (Parent: FGD8 P6).

However, some parents who were denied the opportunity to have their children engage in fellowship with others ended up being teachers at church to teach their children. This occurred since the church had no tailored programme for ASD children. Parents later discovered that many children with ASD within the church were hidden by parents and were denied spiritual education.

When we went to Sunday school and heard them say: “Don’t bring your child to church because he is a problem,” I ended up being a Sunday school teacher for three years and I was given his class. Surprisingly, I later discovered that there were four autistic children including my boy. (Parent: FGD5 P2).

There was a myth that children with ASD could not understand spiritual things and did not need services like baptism. Baptism is a Christian rite that symbolises accepting and surrendering your life to God and allowing God to be your saviour. Religious leaders were hesitant to baptise those with ASD because such children were perceived as not being capable of comprehending spiritual things, and theologically he was above the age that was required for infant baptism. This resulted in parents becoming advocates for their children. A grandmother recalls her outburst at a religious leader. She explained:

I took my grandchild for baptism. The church was shocked that he was amongst the babies. The priest asked me why I wanted to have a big child get baptised as if he was a baby. I told him [priest]. ‘Ask the child his name and his age. If he answers you, don’t baptise him. How long am I going to wait for him to get baptised?’ The bishop felt guilty and later baptised him. (Parent: FGD8 P6).

The narration above revealed the negative experiences parents had with the church regarding children with ASD. The story highlighted how the church had failed to practise inclusivity by designing church programmes and curricula that were not inclusive for children with ASD.

The story was the same with the Christian community in the society who failed to practise inclusivity because of their limited knowledge of children with ASD. A married couple with a child with ASD recalled how they suffered embarrassment the day they took the child for social outings at a shopping mall. The child started to throw tantrums due to an overwhelming environment with too many people present. The child was used to confined spaces. The child ran away from the family and wanted to return to the car. The father was forced to run after him for fear that he might go missing. Later, the mother and other siblings had to stop their shopping activities and follow the father who was struggling with the child. As the family reached the scene where the father was struggling with the child, many on-lookers were praying and casting out demons. The father narrated:

When they were coming (family). They found people praying and casting out demons: “In the name of Jesus. We cast out demons”. I tell you; I was embarrassed, I was afraid and spoke. “What if this thing could happen to my wife when she is alone with the boy?” I had to stop somewhere and shed tears. Tears of how can I lose my child like that? (Parent: FGD5 P2).

This confirms how community members perceived ASD as a condition that was caused by demon possession and that the only cure was an exorcism to free the child from demonic attacks. There appeared to be a tacit, albeit misguided, belief that the community should not be so close to such children until the demons were cast out because they were perceived to be a danger to society. However, most of these people acted out of love and ignorance.

5.2.2 Discriminatory views that religious leaders have toward children with ASD (from the parents’ perspective)

Some parents desired church leaders to be aware of ASD and accept new information on its cause and treatment as opposed to failure to accept such new knowledge. One mother furiously narrated her experience with the church. She suggested and observed the following:

There is a need to bring awareness to churches because they are very difficult to convince. There is a lot of brainwash. Churches in Africa are different from a church in developed nations. Here the church is full of suspicion and it’s a group of brainwashed individuals who are full of suspicions about the child’s condition. Even Autism they would just say these are demons, these are curses. My doctor says, “It’s a condition and my child need this type of intervention” and the pastor will say, “My sister let this not come from your tongue. These are demons. They are from the ancestors.” But my doctor would say, yes, it could be genetics because of this gene and that gene, but the pastor would say, ‘These are demons.’ The congregants after the church service will even distance themselves from you. (Parent: FGD7 P3).

This highlighted how some religious leaders had discriminatory views and limited understanding on the cause of ASD. Parents were determined to create ASD awareness for church members.

Despite majority of parents feeling that the church was not supportive to children with ASD, some parents felt that the church members were helpful to children with ASD. One mother

who had a challenge of a child going missing from home found support from church members to be more supportive to ASD children. One mother said:

What I have done is to introduce my son to church members. This is in case he leaves the gate and disappear. I stay, near airport road. I have told the church members that if you see him, bring him back (Parent: FGD9 P6).

The mother felt that church members were helpful to the child, despite the child obtaining some food items in the grocery without paying for them. The mother found a safer haven for the child from church members who could even allow the child to get some food items without paying for them than to unknown people. She continued saying: *When I visit my friends. I just get reports that he had come, and he got a biscuit. I just pay* (Parent: FGD9 P6).

The two stories above showed that despite the limited knowledge that church members had about ASD, they were equally helpful to both the child and the parents

Sub-theme 2 has highlighted the influence of religion on ASD services that were a barrier to parents' unmet needs. Parents were confused, stressed, and depressed with the type of support they received from the church. Parents expected the church to be more knowledgeable and tolerant towards the child with ASD. However, their expectations were not met since they had fights with religious leaders regarding the cause and treatment of ASD. Only few church members were helpful to parents of children with ASD. Sub-theme 3 explores the understanding of ASD services from the perspective of traditional African beliefs.

5.3 Sub-theme 3: ASD causal explanations from traditional perspective

Sub-theme 3 discusses the understanding of the participants regarding ASD services from an African traditional perspective. It highlights how attributing the cause of ASD to one belief system and way of knowing it would ultimately affect the type of treatment that parents would seek out and consider.

5.3.1 Culturally rooted beliefs about the causes of disabilities

The strong cultural belief of associating ASD with supernatural power was common in the community, regardless of a person's educational level. Parents were surprised to discover that special education teachers held strong cultural beliefs about the causes and treatment of ASD, which they associated with supernatural powers. This was despite the ASD knowledge that professionals like special education teachers had gained from their special education

curriculum about different types of disabilities. The causes, treatment and diagnosis were based on Western scientific content. One mother recalls the advice she received from the teachers:

*They went on to say. **Aah, elo naba mwenye. Ba Mwenye bana bao nibambili. Elo bamafaka vizimba niba business.** [People of Asian origin have a lot of autistic children because they use them to boost their businesses through spiritualism and magic...] I went home thinking: but these people need to know better than to talk like that. If it is a person who has acquired this education and is not applying it accordingly, then, where are we going? (Parents: FGD5 P1).*

The story above demonstrated that some Zambians, including professionals like teachers, were rooted in their African traditional beliefs about the causes of disabilities - especially those health conditions whose cause was not known.

The cause of ASD was perceived to be associated with witchcraft in the African traditional context. It was thought that people who practised witchcraft used magic and charms to cause mysterious diseases or cause death to others because they desired to get rich or wanted to harm others. Professionals observed that most parents believed that their children with ASD were bewitched: *Most of them, they say that the child is bewitched.* (Professional: LPUN1 PP14). A mother recalled what she was told by a neighbour about the cause of ASD. She explained to the group:

***Uja mwana anamuchita** sacrifice ku **satanism. Bana mutenga** voice, Banamutenga **nzeru** (That child was sacrificed to Satanism. The witches managed to extract his voice and intellect). (Parent: FDG7 P3).*

The above story illustrates how the lack of a voice and the neuro condition that the child was suffering from was associated with witches who caused the problem to get rich. Professionals observed that most people in the community referred to ASD children as victims of witchcraft, at the expense of accessing early therapy services from professionals. A head teacher recalled how she managed to remove the notion of witches as the cause of ASD in some parents in the remote villages where she used to go for home-based care programmes. She narrated:

When I went there, they said, no the child is like this due to witchcraft and so on, but it was pure autism. So, I told them to say. “Try these strategies”, and then three months later when I went to evaluate the programme and to see what had happened, the grandmother had done so much that the child showed a lot of progress. The child could now sit. He even stopped biting himself and he looked much better, healthier. The grandmother said, ‘I wish you were here when this child was still young.’ (Professional: LPEDU1 PP2).

Another root cause of disability that the community attributed to was the failure by parents to accept and follow cultural norms and instructions in the pre, peri and post-natal periods. The community felt that parents were the cause of the child’s ASD condition because they could not follow traditional rituals that they were advised to adhere to immediately after the child was born or weaned. One mother recalled the accusation branded against her: *you never did the traditional cleansing (**Kumupeleka Kumalo**)* (Parent: FGD8 P10). Therefore, the punishment of having a child with an intellectual disability was that such children would hardly reach their second birthday before they died. However, parents who had a strong faith in God believed that their children would live longer as God would protect both the child and parents. One parent narrated: *Others say that an autistic child will only live up to two years and later die. I told them that you are not God.* (Parent: FGD8 P6).

The above quote shows the pressure that is exerted on parents regarding a child with ASD.

It was interesting to note that even clinicians associated the cause of ASD with cultural beliefs, i.e. that it was created by witchcraft. One mother narrated:

The tongue-tie was removed at the clinic..... We went back to the same clinical officer. We said she is still mute, and she is not talking. Could it be that they have grown again? So, the clinical officer checked and discovered that the tongue-ties had grown again. I was told that they came back because I had looked at the blood during the first operation. [time of removing them] This time, I did not look at the blood during the operation. All I needed was for my child to talk. (Parent: FGD7 P3).

Another Zambian mother who once lived in Zimbabwe and had a child whilst living there was equally shocked with the advice given to her by a clinician. She recalls:

I remember asking the doctor. What should I do? Do you know the answer he gave me? He said to have another child. I said what do you mean? He said, 'Have another child, you will never know that he may be the one who may teach the other one how to talk or walk. It was a struggle. Then I said, 'Let me have another child (Parent: FGD4 P5).

The above advice from a professional that part of the cure to ASD was having a child might not have been well explained to the parent. The professional might have meant that a child needs social interaction with others.

Professionals felt that it was the duty of Ministry of Health to improve quality services for parents of children with ASD: One professional felt that the Ministry of Health should know its responsibility of providing health services in the community

This is a public health issue. We shouldn't run away from it. To say that it's not a public health, does not mean that it's the parents who should be going around looking for the services. No! The Ministry of Health should ensure that these services are available, and people know where to go (Professional: LPUN1 PP15).

Another professional suggested the increase in capacity building of health professionals with ASD skills is critical. He said:

It could be nice to train people in health care from different places. I am not saying that they must diagnose, but at least they advise parents and then do some follow-up. I would like to say that it is true that not everyone can a diagnosing officer (Professionals: LPHLT1 PP20).

To improve on human resource development, the University of Zambia started a program that trains students in clinical nuero psychology that helps parents of children with ASD. One lecturer from the University of Zambia said:

You see we started a master's in clinical Neuro Psychology in 2009 and MA Psychiatric 2010. So by stating that, we started recruiting trainees to do such courses and they became our potential tutors. So now our mass of academicians has increased so that we are reaching out to so many students. Our training of students in mental health is far more robust than it was ever before. (Professionals:LPUN1 PP14)

5.3.2 Community sympathy

Traditional healers (Sing'anga) in the Zambian context are people who use herbal medicine to cure diseases, mostly strange ones that cause harm to individuals and the family whilst herbalists are people who know unconventional medicine and uses herbs to cure diseases and do not do divinations or use spiritualism when providing the services. Traditional healers acquire expertise through an apprenticeship with seasoned traditional healers or through ancestral spirits who give instructions and reveal the causes of diseases. Traditional healers were perceived to have stronger powers to counteract witches. When there is a challenge in the community, the community members try to help the affected parent collectively. Different honest suggestions about available services will be given to parents. Parents were advised to take their child to traditional healers for the cure of the condition:

They will always say: 'awe amapola bana aba'. [These children do get healed]. Others would say 'nichuma, mulembeni ndembo' [Witches are playing with your child because you are rich, take your child to traditional healers to tattoo him for protection], and we did that. You know desperation, you want the best for this child. (Parents: FGD5 P1).

The quote above shows how the community were honestly providing advice to parents from a traditional perspective on what would have caused the child's strange condition, and what parents were expected to do to protect themselves and the child from further evil challenges.

Most parents believed that the cultural advice which they received from the health professionals, religious leaders, community members and teachers was given in good faith:

I think it is not the fault of the community that at times they advise us to take the child to witch doctors (traditional doctors). At times they do it in good faith so that our child can be okay. We don't know about this condition as we do with other conditions. The community must be made aware of this condition. (Parent: FGD1 P3).

This observation by parents indicated that, despite the myths surrounding the causes of ASD, the advice given by the community to parents was done in good faith to help parents have their child cured and treated for the condition.

In summary, juggling multiple sources of ASD knowledge (Theme 1) has highlighted how ASD was understood by the community. This includes the meaning that parents and

professionals attached to the term ‘ASD’, and the challenges participants experienced to access the Western medical perspective of the disease.

The key observation in Theme 1 was that parents and professionals had challenges understanding the causes of ASD from a medical perspective as defined in diagnostic ASD manuals, which had an impact on the specific treatment options they subsequently explored.

5.4 Theme 2: Community and informal support services

Theme 2 focuses on parents’ experiences with inadequate informal support services. This led parents to experience emotional and social barriers as they had access to limited informal support. Three sub-themes emerged, and these were:

1. Fear, anxiety, and stress
2. Stigma and abuse.
3. Inadequate family support groups within the community.

Table 5.3: Structure of Theme 2, including sub-themes, and categories

Theme	Sub-theme	Categories
Theme 2 Community and informal support services	Sub-theme 1 Fear, anxiety, and stress	▪ Uncertainty of the future. ▪ The urgency for counselling services ▪ ASD children are God’s special gift
	Sub-theme 2 Stigma and abuse	▪ Maltreatment and discrimination ▪ Ill-informed community
	Sub-theme 3 Inadequate parent-led support groups	▪ Limited parent support groups ▪ Urgency for collaboration

5.4.1 Sub-theme 1: fear, anxiety, and stress

The stories of parents shifted from seeking ASD knowledge to accessing community and informal support. Parents lived isolated lives because of insufficient informal support services that were available in the community. This caused fear, anxiety, and stress about their future and that of their child. The greatest fear, anxiety and stress parents experienced was what

would happen if their child outlived them. Parents did not know who was going to care for the child.

5.4.2 Uncertainty of the future

All in all, I still cry even now. I don't know how to pray anymore. My prayer is for God to give me a long life. I have to live a long life for my child. If God calls me to sleep too early who is going to take care of my child? (Parent: FGD7 P3).

I have no one who is going to take care of my child from my family. Some family members bluntly told me that, the day I will die, I must die with my child. They said. "We don't want you to leave us with problems". (Parent: FGD8 P8).

Other parents had this to say: *We have heavy thoughts on who will take care of them (ASD children) when we die? (Parent: FGD6 P1).* Another parent added: *We are worried about what does the future hold for the child. (Parent: FGD6 P4).*

The quotations above reveal the parents' anxiety and stress because of fear if the child outlived them. Parents were uncertain about their child's future.

5.4.3 The urgent need for counselling services

To reduce anxiety and stress, parents were determined to access counselling services. Professionals acknowledged the need for counselling to improve the quality of life for the parents.

When it comes to the process of grief, they go through a lot. I try to be there and counsel them being a therapist. I provide is not only just child support, but also parents' support. You make the parents your co-therapists. (Professional: LPHLT1 PP20).

They feel stressed of course because just to have a child is stressful and to start thinking of where to access the services and how am going to help my child. It is more stressful on their part, I think. (Professional: LPEDU1 PP1).

Mmm... I think parents with such children, it's quite a challenge for them because at the end of the day they don't know what this is, and they don't know to what extent it will affect their child. So, I think they are in that fear, and they would want somebody

to help them. Maybe somebody to talk to them, just to encourage them. Saying everything is going to be okay and... yeah. [Yes]. (Professional: LPSW1 PP11).

Parents reported that there were few skilled professionals who had knowledge about ASD and could provide formal ASD counselling services at pre, peri and post-diagnosis stages: *The problem is that when you go to the hospital, they don't tell us that this is autism and counsel you.* (Parent: FGD4 P7). Parents expected health professionals to provide pre and post ASD counselling services to expecting mothers and couples. A parent suggested:

Counselling parents is very important because when you are expecting a child, you expect that your child will be okay and when you have such a child, life changes, it is no longer a straight line. (Parent: FGD 6 P1).

Furthermore, parents required counselling services from qualified professionals who were knowledgeable about ASD, sensitive to their needs and who provided adequate information about ASD.

Am I going to be understood? I am going to be scolded? What type of information I am going to get from there? I need someone who is emotionally alert. Emotionally alert, not to discourage me, but to encourage me. (Parent: FGD7).

The story above revealed the stress that parents underwent as they accessed counselling services. Parents were filled with anxiety each time they visited the hospital as to whether professionals would provide counselling services of excellent quality as they sought quality services to raise their child with ASD.

5.4.4 ASD children are God's special gift

Despite the stress that parents suffered in accessing informal support services, they used different strategies to cope with stress, fear, and anxiety. The parents' religion and faith in God helped them accept a child with ASD as a test from God, and at the same time as a God-given gift:

I cannot question God. God is God. Me, I believe that where God gives you a challenge, there is still a way. He is just God. Maybe he gives us these children so that we become closer to him and if we can handle these children, we can handle other challenges in life. (Parent: FGD9 P4).

Anxiety and stress (sub-theme 1) left parents with fear and rendered them hopeless, and in despair regarding their child's future if the child would outlive them. Parents wanted better counselling services that was and more accessible. Their faith in God assisted them to cope with anxiety, stress, and fear, as well as helping them accept an ASD child as a special gift from God and a test of their faith. Sub-theme 2 discusses the stigma and abuse parents and the child experienced in the community.

5.5 Sub-theme 2: Stigma and abuse

Sub-theme 2 focuses on the stigma and abuse which both the parents and the child with ASD experienced. The theme explored how the children and parents were stigmatised and abused by the community.

5.5.1 Mistreatment and discrimination

The parents explained that child discrimination and mistreatment were worse in mainstream schools, where teachers and school administrators could not accommodate learners with ASD. A mother recalled how her son was discriminated against by school authorities who forced her to get a transfer of the son to another school. This was because the child with ASD was considered as danger to the school. The mother felt discriminated against, frustrated, and disempowered by the negative comments and actions of the school authorities. She narrated:

We took him to a new school run by the Catholic Church. That was a bigger blow to him. At the new school, the child faced challenges, he didn't even know the location of the toilets and things became worse. He started even relieving himself in his pants.

He started fighting other children at school. He did not know where to find the toilets. The teachers and the administrators at the school later, just told us that the child was a danger to the school and was equivalent to 20 children. "We cannot keep changing him, we cannot keep handling his mess. I think give us time. Get your child." That was one of the most shattering experiences in my life because I told God that, 'if it were possible, I would have put back my son in the womb because that is the only place where you know not any rejection' (Parent: FGD7 P3).

The ‘womb is the only place’ where rejection is not known emphasises the strong rejection these children with ASD faced from schoolteachers, caregivers, and the community. Children with ASD had no place that was willing to accept them or accommodate them. Life for individuals with ASD was marked by discrimination and mistreatment, to the extent that, rather than to be exposed to such harsh treatment, it would have been better if they had not been born.

This social mistreatment was also evident in schools that the children attended. Special education teachers who did not know how to educate a boy on sex education stopped the boy-child from socialising with girls. A mother was surprised to discover that teachers were socially and emotionally abusing her son after teachers discovered that the child was becoming intimate with a particular girl in class. She narrated:

I found the teachers despising him. I asked them, what has he done? They were a little hesitant to tell me. That is when they were saying, ‘No, you know he wants to be seated very close to one particular girl. He always likes to be like this...’ (showing intimacy closeness). I was alarmed (Parent: FGD5 P1).

The quote above explains that teachers failed to teach issues of sex education to a child with ASD because they did not know how to communicate such messages to learners, especially those learners who were in adolescent stage.

Children with ASD were abused and neglected by many people in the community, including those who were employed by the parents to take care of them. Working mothers complained about the burden of leaving a child at home with an employed caregiver who could physically and emotionally abuse the child. A mother who was so upset with the behaviour of her former caregiver had this experience. She recalled:

I left my son with our maid whom I did know that she was abusive to the child. When I came back from the hospital, I found that my son could not speak. The boy was mute. This is the boy I was talking to some five days ago even the day I was going to labour [giving birth] (Parent: FGD7 P3).

While professionals agreed that there is discrimination of children with ASD by community members, they felt that at times discrimination is perpetuated by the parents themselves who have failed to accept the condition of the child and become the ‘voice’ of the child in the community. Professionals felt that some parents took time to accept the child’s condition. One professional observed: *Some parents are in denial. They know that the child might be autistic, but they don’t want to face reality* (Professionals: LPHLT1 PP8). Another professional observed that some parents feel professionals do not assist them or do not know about ASD because they go to wrong professionals for diagnosis and treatment. One Professional said: *Others don’t know where to go for support services* (Professionals: LPUN1 PP15). Professionals felt that parents have ignorant about specialisation among health professionals. Parents think that all professionals have specialisation in all health-related conditions such as ASD.

5.5.2 Ill-informed community members

The discriminatory behaviour and mistreatment towards children with ASD were mostly coming from the child’s peer group which was a cause of great distress. A great grandmother explained how she was often aggrieved by the community’s reactions towards her ASD great-grandson. She exclaimed:

And when he is outside, the way in which the community will try to get hold of him, it’s like he is a mad person. They will come in a group and will shout cha choka chi . Icho Chi Godfrey [Godfrey is out. Look at him.[The term ‘Chi’ in this context would refer to someone/something bad, ugly, disagreeable, or offensive] Now me being a parent, I feel very bad. (Parent: FGD6 P4).

The sad story above illustrates the ignorance of the siblings regarding ASD because they were not educated on how to live with children with ASD in their respective communities. Terms used by children such as *Chi* are derogatory terms in the local language.

Parents could not only be discriminated at home but also when they use public transport. Bus conductors also abused both ASD children and their parents when they used public transport:

I fear that bus conductors are so rude, and it is difficult for them to communicate with him. (Parent: F GD4 P1).

*Some drivers and passengers will be saying, **uyu mwana alibe ma manners.** [This child is ill-mannered] So what I say is.... Get this child and teach him the manners since I have failed. (Parent: FGD3 P1).*

The story of bus drivers was indicative of the need to create awareness of ASD among the public and communities.

It was a traumatic experience for relatives or family of the child with ASD to live in communities where members had a negative attitude towards children with a mental health condition. An aunt of an ASD orphan child had this story to share with the group:

The community would shout at me and say: Why are you still cleaning pants for such a big boy? You must be beating him so that he stops messing up in the pants. At times he runs away from home and goes to sit on the main tarred road [Great East Road]. You know, it's just by the grace of God that sometimes some good Samaritans remove him from the road and then you find that he may still go back. Community members will start laughing at him, booing him and at times they stone him. As a parent, you feel bad. (Parent: FGD1 P1).

Negative comments by the community towards a child with ASD forced parents to prevent their children from playing with peers in the community because they were afraid of getting arrested if the child committed an offence while playing with others.

Mothers were not spared the emotional and social mistreatment by the community - neighbours with whom they shared apartments. Neighbours avoided associating with ASD parents because of the child's strange noise, mostly at night. This led parents to live isolated lives. One mother who was renting a house in a township lived an isolated life because of the neighbour's reactions towards her child. She recounted:

If you are renting a room and the child cries the whole night making noise, you will find that the next morning the neighbours will not even greet you. Even when you greet them, they will not answer. Then you know it's because of the noise in the night. People in the community

use terms like *chimwana chao cholemara* [This disabled child is a noisemaker in the night. (Parent: FGD3 P4).

In Zambia, it is part of the custom to spend nights and days at the funeral house until after the burial. The custom is more adhered to when the one who has died is a relative or an immediate neighbour. Parents continue living isolated lives, even during community social gathering events such as funerals. In one incident, funeral attendees were intolerant and were repulsed by a child's screaming and repetitive behaviours at the funeral house, which was inappropriate. The comments by the funeral attendees were perceived as negative and discriminatory by the parents of children with ASD. A mother narrated her encounter at one funeral. She explained:

You know these children are a challenge and the community can talk. I remember I went to the funeral. When he saw people crying, he could also cry louder, and people started commenting saying; 'Look at this child the way he is crying. He mourns as if he is the owner of the funeral'. To avoid talking, we don't sleep over during funerals even if it's for your brother. We have to just come in the morning or afternoon. You just leave the child at home, then quickly go back home to check on him. (Parents: FGD8 P1).

The comments by the mourners towards a child with ASD could be attributed to a limited understanding of ASD.

The lack of acceptance of a child with ASD by the community, coupled with the accusation of bad parenting of the child, forced parents to live isolated lives and to withdraw the child from the community. A mother explained:

I just stay with my child, some people laugh at him, some think you are lazy, and the child was poorly managed during childhood; 'Unamupusika' (poor upbringing). (Parent: FGD3 P5).

Parents who wanted to access basic services, such as going to the barber to give the ASD child a haircut, were denied the service, primarily due to these service providers being ill-informed about how to handle children with ASD. A mother remembered how she screamed at the barber man and learned how to cut the hair of her son. She narrated:

The other experience I remember having, was in a barbershop because he was ever fidgeting. So, the barber man turned to me and said: 'This child, take him to another barbershop. Don't bring him here. We don't want problems because if I hurt him.... He is a problem'. I screamed on top of my voice. I said, 'Haven't you noticed how the child is? Where do you expect the child to go?' So afterwards I got him a machine and now am a professional barber lady. (Parent: FGD5 P1).

The above quote shows how a woman entered what is termed as men's job in Zambia of hair cutting. The phenomenon is not common amongst the ladies.

Parents expected community members to accept children with ASD, as they did typically develop children: *The community should accept the children the way they accept their children.* (Parent: FGD2 P3). This was because raising a child with ASD was a challenge that needed support from all members.

Parents also had the added huge task of counselling their children, making them understand their condition and the cause of discriminatory behaviors against them from the community.

We have activities at home where we instill some positive thinking in him and assure him that there is nothing wrong with him. We tell him to forget about others who may talk ill of him. The positive words have greatly helped him. (Parent: FGD1 P3).

Sub-theme 2 centred on the stigmatisation, discrimination, and abuse of both the parents and children. Parents and children were discriminated against by the community because of a limited understanding of the cause of ASD. Parents expected the community to be aware of ASD and to be supportive of them. However, parents experienced marginalisation, discrimination, and isolation from the community. To mitigate such challenges and live a positive life, parents used different mechanisms to cope with the community's negative attitude towards the child's condition. Some of them was joining support groups.

5.6 Sub-theme 3: Inadequate parent-led support groups

Sub-theme 3 explores the importance of creating parent-led support groups in the community. The stories are based on the lack of family support groups and limited parent and professional collaboration. Both professionals and parents narrated the importance of having a structured parent support group, and the need to promote parent-professional collaboration.

5.6.1 Limited parent support groups

Parents and professionals acknowledged the limited number of structured parent support groups and non-governmental organisations for ASD within the community that offered support services to ASD parents and had meetings regularly. When parents were asked if they knew of any family support groups in their community, they said: *For me, I am blank. I don't know such organisations* (Parent: FGD4 P1). This was supported by professionals who said: *I don't know any support group where they meet regularly* (Professional: LPHLT1 PP8).

This illustrates that support groups did not exist in their respective communities. However, other professionals were aware of the non-ASD disability parent-led support groups within the community, which had good parent support group activities. One professional recalled:

For family support groups, I would refer them to some existing groups. For example, the group I belong to. In this group, parents have come together to provide respite care services. They have programmes such as sleepovers. This is where parents go and spend a night at another friends' home to go and provide respite care. Other activities involve day-care support and assisting fellow parents to look for honest caregivers to employ. However, there is a need for the families to be helped by the professionals so that the advice and support they give each other is appropriate. (Professional: LPM1 PP10).

The common ASD parent support groups available at the time were those on social media. One professional commented: *I only know the WhatsApp group where the parents share their experiences* (Professional: LPHLT1 PP8). However, the challenge of the social media grouping was around management control, because of the overload of information and business making schemes. A mother explained:

The only challenge with WhatsApp groups is that at times there was this lady from India. I think it was a global group and she was flooding us with a lot of information. I think it became a money-making thing. I am on two WhatsApp groups, one which was created by Special Hope and another one which is some kind of a pressure group.
(Parent: FGD7 P2).

I wanted to find out further about how parents of children with ASD helped each other in the absence of the ASD structured parent support groups. One mother from the township said: ***III badi.*** *[It's a challenge]. At times the school calls us* (Parent: FGD3 P1).

Parents observed that fostering networking was a challenge because of the lack of adequate venues for holding frequent meetings. Parents identified smaller houses and shared rooms with neighbours as a barrier to frequent meetings. Other parents had no personal accommodation which they could offer for meetings. One mother challenged the group and said:

Let us just be honest, women.... Our houses are too small, just a two-roomed house. How do you accommodate someone in a one or two-roomed house when you are married? (Parent: FGD3 P1).

5.6.2. Urgency for collaboration

Professionals and parents felt the urgent need to promote collaboration between the ASD parent-led support groups and the already existing professional-led support groups. Professionally established organisations could be used as a channel to lobby policymakers on behalf of parents' support groups and address the barriers to support services for parents of children with ASD. A paediatric professional suggested:

These supporting groups need to work with the Zambia Paediatric Association which can assist to lobby from the Ministry of Health. We need to work together and not in isolation and if we work together, we can advocate.... (Professional: LPHLT1 PP16).

In summary, limited structured parent-led support groups in Zambia were exemplified as a barrier to creating frequent social grouping networks among parents. However, parents agreed on the need to form support groups that could be used as tools for self-emancipation.

5.7 Theme 3: ASD specific knowledge and formal services

Theme 3 accounts for the stories regarding the gaps in ASD specific service provision that parents observed. ASD specific knowledge and service is a theme regarding the wishes of parents to have specific ASD knowledge and access formal support services that would promote independent living of both the family and the children.

Table 5.4 gives details of theme 3 and its categories. Three sub-themes and seven categories emerged from the data that was generated. The themes are:

- 1 Developing skill to manage ASD
- 2 Shortage of personnel and resources
- 3 Inadequate ASD policy development and implementation

Table 5.4 : Structure of Theme 3, including sub-themes and categories

Theme	Sub-theme	Categories
Theme 3 ASD specific knowledge and formal services	Sub-theme 1 Developing skills to manage ASD	▪ Capacity building ▪ Self-reliance
	Sub-theme 2 Shortage of personnel and resources	▪ The desire for specialised services ▪ Costly services ▪ Lack of culturally appropriate diagnostic tools
	Sub-theme 3 Inadequate policy development and implementation	▪ The desire for specific ASD policy frameworks ▪ The urgency for affirmative action on the existing disability policies

5.8 Sub-theme 1: Developing skills to manage ASD

Sub-theme 1 is based on parents' desire to build capacity. The aim was to develop the necessary skills needed to care for a child with ASD as well as develop skills of self-reliance that would enable parents generate income from business ventures, hence self-sustaining.

5.8.1 Capacity building

Parents had no training and knowledge on how to handle the daily activities and living needs of a child with ASD. Single parents with adolescent ASD children found it even more culturally challenging to educate a child of the opposite sex regarding sex education. One mother had this challenge of educating a boy child regarding sex education. She observed:

He is 12 years...I noticed that now hairs have started growing in places and so am thinking. Oh my God. How do I go about it? (Parent: FGD5 P1).

The above quote shows that parents experienced challenges to talk about sex education and physical development that happens as the child is growing, i.e., through puberty changes as an adolescent. This shows that parents had limited training on how to handle issues of sex education in children with autism.

Parents observed that they lacked knowledge in many areas of ASD and needed to be capacity built with knowledge and skills in areas such as what ASD was, its cause and treatment, and how to communicate sex education messages to their children. The parent said:

I think we need training on what is autism, its causes, treatment, symptoms. This will help us to know how to help our child and that of our friends and neighbours. (Parent: FGD1 P3).

Professionals equally observed that parents had limited training on how to manage children with ASD. To mitigate such challenges, some parents were enrolled on an ASD online training programme. The programme was translated into local languages to accommodate illiterate parents who could not understand or read the English language. The online training programme was started by a head teacher in partnership with a university in the United States of America. She explained:

We have this University of Minnesota website where they run different courses on ASD. We are aware to say that some parents do not know how to read. So, we bring them together and then we go through the course together and we even explain in local languages so that each person understands their child's problem (Professional: LPEDU1 PP2).

5.8.2 Self-reliance

Parents also wanted entrepreneurship training skills to enable them to become self-sufficient financially, rather than be at the mercy of the government or donors. Parents had this appeal to make to the government and ASD supporting partners: *Train parents in entrepreneurship, business so that the money raised from such can be used to help their children.* (Parents: FGD1 P1).

Professionals were of the view that the Zambian government should develop long term goals that would mitigate parents' future financial burdens and make them self-reliant. One professional suggested the following:

We need to start small; we need to start somewhere. We have plenty of lands. It could be agriculture. Give them a piece of land, and give them free seeds, fertiliser. It could be like a loan given to them, which they can pay in ten to five years. Parents need some incentives so that they know that I have an autistic child and am disadvantaged or giving an [an opportunity for] employment to one of the members or maybe to a sibling or a parent so that they support themselves and they can use the resource to send him [child with ASD] to school to learn of other skills. (Professional: LPUN1 PP14).

However, social welfare officers indicated that the the Government of the Republic of Zambia., through the Ministry of Community Development and Social Services, had established financial projects to mitigate the challenges faced by persons with disabilities and vulnerable families. The Government run a social cash transfer programme, which is allocated to specific vulnerable groups such as the aged and severely disadvantaged persons with disabilities, who had a certificate from the medical doctor certifying the disability. The funding for persons with disabilities was higher than that of other categories of vulnerability. Two social workers had this to say:

The Government has put in place things like settlement schemes, social cash transfer programmes. (Professional: LPHLT1 PP23).

From the social perspective, what we are already doing is that certain disabilities that are certified by doctors are given more money as compared to others. The social cash transfer they received is K350

(35 United States of America dollars (USD) every two months as compared to a household which is given K180 (18 USD) every two months. (Professional: LPSW1 PP17).

The two quotes above showed how the social cash transfer funds had enabled persons with disabilities and their families to have an income for their livelihood. A social welfare officer described how a young divorcee mother with a child with ASD benefited from the large social cash transfer funds, which assisted her to have enough money to start a business.

*She was able to open a small shop which we commonly call **Tuntemba** [Small permanent or mobile makeshift grocery shops]. We did this as a department to empower her rather than giving her funding every month which was going to be a challenge for the department. So, she was given some groceries worth K2000 (200 USD) where she was able to start her business. (Professional: LPSW1 PP12).*

In summary, ‘Developing skills to manage ASD’ are stories that have revealed how parents identified the needs to be trained on. Parents wanted to be capacity built on how to manage the child with ASD as he or she transitioned from one developmental milestone to the other. Parents equally wanted entrepreneurship skills imparted to them so that they could become financially independent in the future.

Sub-theme 2 explores how the shortage of personnel and resources at institutions that were supposed to manage children with ASD impacted quality service delivery.

5.9 Sub-theme 2: Shortage of personnel and resources

Sub-theme 2 explores the shortage of personnel and resources, which became evident to parents during the process of searching for ASD services. Accessing quality ASD support services mainly in the health, education and social welfare sectors was associated with a shortage of specialised services, costly services, and a lack of culturally appropriate diagnostic tools.

5.9.1 The desire for specialised services

One of the empowering stories was the opening of the Developmental Intervention Clinic (DIC)* at the University Teaching Hospital, located in the capital city of Zambia, Lusaka. This was the only public health institution where diagnosis and therapy were provided. The

DIC had had some good impacts on service delivery, but parents demanded services that were consistent and timely.

Well... The clinic where I am working is the Development Intervention Clinic (DIC). It is the only one of its kind in the country. This is because our clinic is a multidisciplinary clinic, so we have different professionals working together. We have physiotherapists, speech therapists and occupational physiotherapists. Then, apart from that, we also have a Neurology clinic run by two doctors attached to the children's hospital at the University Teaching Hospital (UTH) (Professional: LPHLT1 PP21).

Parents complained that the services provided to them by DIC were not adequate because they could only be provided once every fortnight or after a month, instead of daily. One mother complained:

Previously, sessions were every week, but now it's over two weeks. This means that if your day falls on a holiday, then you may miss almost a month without any intervention programmes. (Parent: FGD7 P1).

Due to the overwhelming response from parents wanting to access these services for their ASD children, the health professionals at the DIC acknowledged the poor service delivery because of the shortage of human resources.

Well... We cannot cope with every child that comes here, but as far as I know, we have a lot of children that come from the Copperbelt, from Central provinces because this is the only place that you can find such services. (Professional: LPHLT1 PP21).

Rural parents complained about being systematically denied access to ASD diagnosis and therapy services closer to their homes. The lack of diagnostic services in rural areas resulted in late diagnosis or no diagnosis at all for a child with ASD.

I think those facilities should be in every district everywhere, because having worked in the rural set-up, sometimes I get touched when I

look at people who are deemed mad or something like that. I think to myself; this could be potentially undiagnosed autism and people just don't know and this person may have so much potential because they are in an environment where they are not exposed to services like assessment. (Parent: FGD5 P1).

The cause of having centralised ASD services that are found in the Lusaka district only was the lack of adequate critical skilled health professionals to work with children with ASD. The Head of Department (HOD) at the University of Zambia (UNZA) School of Medicine expressed concern over the inadequacy of human resources for critical skilled labour in the health sector. He recalls: *We don't have psychiatrists in the country who are specialised in child psychiatry. (Professional: LPUN1 PP14).* A private paediatrician added: *There is only one paediatric neurologist in this country, and she is not a Zambian. (Professional: LPHLT1 PP16).*

Parents also experienced challenges in the education sector. There was a limited number of special education teachers who could offer child-centred education programmes, leaving children with ASD unable to access educational opportunities. One parent observed:

I saw somewhere, something called IEP (Individualised Education Programmes). Apparently, they have something like that in other countries. I am sure I would like that for my child because I have observed that different children have different needs, and they see things differently and they have different attention levels. Unfortunately, there aren't enough caregivers to give that individualised education system to these children, especially for autistic children. (Parent: FGD5 P1).

Parents, mostly those in rural areas, could not see the benefits of taking their children to school, because they had observed little or no academic progress. Educating a child with ASD was viewed as a waste of time and resources: *These children need help. My child is in Grade 6 and his friends are in Grade 7. He is still learning the same things. (Parent: FGD1 P2).* However, parents wanted their investment in education to be equal to the type of education the child was receiving. Parents did not stop taking their children to school.

School administrators (head teachers) acknowledged the concern of parents regarding the stunted academic growth of their children with ASD. This was because parents were comparing the progress of a typically developing performance in class to their child with ASD. Parents did not know that some children with ASD may not progress at the same rate with typically developing children if early interventions delayed

5.9.2 Costly services

The ASD health services provided by public health sectors were too expensive for many Zambians to access. Parents faced challenges in accessing the drugs, which were supposed to be provided for free according to government policy. When they arrived at the hospital, they found that the prescribed drugs were normally out of stock. Parents had to frequently purchase these expensive drugs using personal finances. Parents, mostly from rural districts, complained about the high cost of the drugs, considering that the majority had limited income-generating ventures and were not on any insurance cover. One parent noted: *He was put on medication which costs K300 (30USD). Therefore, the only support I would seek is money to buy medicine.* (Parent: FGD4 P4). The above quote shows that parents could not afford to buy the prescribed drugs after finding that the public hospital pharmacy had no such drugs.

Equally, the private sector was more expensive than the public sector, and many of the ASD private sector service providers had taken advantage of the limited services in the public health sector to open their assessment centres. Most of the assessment centres were run by international organisations who charged higher prices, quoted in the USD currency because they know that they would get more money from clients, considering the fragile of the economy where the value of the Zambia currency normally depreciate. Two parents had this complaint:

If you need the best quality services at Autism Children's Centre, you need to pay at least K6000 per month (600 USD) which means in a year, we were paying over K60, 000 (6000 USD) for therapy activities. The most painful thing is that even if the school is on recess for two weeks, we still had to pay the full amount. (Parent: FGD7 P2).

When I went to inquire, they said it was about 50USD or 100 USD per 30 minutes. They were quoting in dollars. (Parent: FGD7 P1).

The quotes confirm that health services provided by private institutions were very expensive and were beyond an ordinary Zambian citizen even those who were working and had high paying jobs. The high cost of accessing therapy services was made worse by the fact that the

insurance companies, both private and public, had no premium package to cover ASD related expenses. A professional who worked in private practice sympathised with the parents: *The health insurance does not cover the therapy, the same with occupational therapy. So, they must pay for themselves.* (Professional: LPHLT1 PP16).

It was observed that public and special schools were underfunded and those funds that were available were hardly released on time. At times, it could take over four months for the funds to be released. A school administrator at a public special school narrated:

The funding from the government is very, very unbearable. It is not good. Because, sir, against 200 pupils and then you are just giving K2000 (20USD) quarterly. (Professionals: LPEDU1 PP5).

The story was the same at a grant-aided special school. The head teacher complained that running a special school is very expensive as children with disabilities require a lot of material support for them to get educated. She complained that the money was not enough and many times they were supported by well-wishers. She explained: *The highest amount we have ever received is K2500. (\$ 25 USA).* She continued complaining: *Sometimes we receive K1500 ((\$ 15 USA) per term.* (Professionals: LPEDU1 PP2).

The above quotes revealed the challenges that school administrators face to run special schools and support children with ASD. A school receiving as low as K1500 in three months to do all administrative work including academic activities for children with disabilities which includes ASD.

The other high costs that parents experienced were from the transport sector. Transport fares were ever-increasing because of the high cost of fuel. One of the greatest challenges' parents faced was the high cost of public transport. Professionals sympathised with parents who meet all the transport costs without government support. A professional observed: *One of the critical barriers is the lack of transport. You know the economy is biting everyone and what about those that are already in the low-income group. Professional.* (Professional: LPHLT1 pp 21).

This illustrates how high transport costs, which were frequently adjusted upwards by the owners of minibuses and taxis, indirectly and negatively impacted access to education for a child with ASD.

During the interviews parents shared their lived experiences on the costs of transport mostly from the public sector. Each time they travel with a child they must pay double the costs for the child and the parent. There was no half-price or free transport for parents and the child who were going to school. A mother narrated how they needed transport:

The issue of transport, you have to pay for two people every day to bring the child to school. You and the child despite that the child is young. I come from Chelstone [20 km to UTH special]. Each day I spent K30 (\$3 USA) for my transport and K30 on her that is K60 every day. It's not a guarantee that you will only spend K60. She may start crying for some foodstuffs, you must buy for her. So, it's K70 (\$ 7 USA) and above. If we can have a bus here that will be fine. We had a meeting last time here where we were promised a bus, but nothing has been done. (Parent: FGD8 P10).

The story is indicative that parents experienced challenges even in accessing transport.

5.9.3 Non-standardised diagnostic tools

Parents and professionals complained of the use of non-standardised and culturally unfriendly diagnostic tools that were used: A professional had the following observation:

The challenge that we have in Zambia is the lack of a standardised tool and competent professionals to administer the tools. We don't know which tools are used to diagnose ASD. We depend on checklists. Most of the diagnosis is based on formal and informal checklists. Some tools used are picked from the materials we read in the literature. One instrument which has been helpful to me is the SNAP. All these are foreign tools, and we have few trained people to use them. (Professional: LPM1 PP10).

The finding raised concerns about the appropriateness of some of the tools used to diagnose ASD, and the limited knowledge professionals had of using the tools. Professionals acknowledged that they did not have standard diagnostic tools for ASD. This meant that each professional used his or her tool for diagnosis and treatment. The effect of this approach meant that children either received the correct diagnosis or the incorrect one.

The other challenge faced by the professionals was the lack of adequately trained personnel to administer diagnosis and assessment tools.

We don't have any tools, there is the Wechsler Intelligence Scale for Children which I don't think is a very good tool to diagnose autism. We do have a Child Autism Rating Scale but not many are trained on how to apply that. So, we just use simple clinical skills, we use diagnosis DSM-tool. We don't have a proper rating scale.
(Professional: LPUN1 PP14).

In summary, sub-theme 2, the shortage of personnel and resources, revealed the shortage of human resources, who were supposed to provide adequate therapy services. Another barrier to support services was the high cost of accessing the services in the education, health, and transport sectors. The last barrier experienced by participants was the non-availability of standardised diagnostic tools. This had disadvantaged **children, who were either underdiagnosed or wrongly labelled as having ASD.**

5.10 Sub-theme 3: Inadequate ASD policy development and implementation

Sub-theme 3 highlights the inadequate ASD policy development and implementation related to the prevailing ASD services. The inadequacy was observed in the lack of ASD policy frameworks.

5.10.1 The desire for specific ASD policy frameworks

The first barrier is the lack of a policy framework. There is no policy framework on ASD and no guidelines towards Special Education Service provision and how to handle autism spectrum disorder challenges. In the absence of the Policy Framework, services provided to families of children with ASD are at the goodwill of individuals or institutions. (Professional: LPM1 PP10).

Parents of children with ASD expressed the desire for the government to enact specific ASD policies that addressed their needs, and to compel all service providers to accept and provide appropriate services to all children with ASD in line with the law.

The lack of a policy framework has had a negative impact on the type of education services provided to ASD children in Zambia. One education policy that parents felt was unfriendly to ASD children was the one that governed the Examinations Council of Zambia's (ECZ)

National Examination Assessment Guidelines. The ECZ administered a centralised examination to Grades 7, 9 and 12. Parents were frustrated to see that their children were being subjected to long hours of examination when most ASD children were hyperactive and could not manage to write a two-hour examination paper whilst stationed in one place. One mother had this to say:

If I were president, I would ban the three hours centrally set national examinations for children with ASD: There is no way a child with ASD should write the same examination as a typically developing child.
(Parent: FGD7 P1).

Parents wanted a statutory instrument to be signed regarding social protection for persons with ASD. This instrument would provide them with funding and access to hired professional caregivers. This would empower them to live an independent life.

First, there will be a need to have an SI (Statutory Instrument) about people with autism, for them to be socially protected. ASD children should have an income. We know that adaptive skills are difficult to come by, so if am an autistic adult, I should be able to gain some income and live my life and if I need a caregiver other than my parents, let me do that. (Parent: FGD7 P3).

Parents further desired a national inclusive policy towards service provision:

My first thing is to put in a policy such that children with autism should be having what the other children are facing Number one will be school. (Parents: FGD5 P2).

The enactment of an inclusive policy in accessing support services may reduce instances of parents hiding their children in their homes: *I would propose a legal framework that no parent/caregiver hides such a child* (Parent: FGD3 P2).

Health professionals felt that there was a need to have a specific health policy framework on how ASD is to be administered under the Ministry of Health:

I don't know if there is any policy framework. Even in medical notes. I haven't read the new National Health Policy, but it was not there in the previous one. (Professional: LPHLT1 PP16).

Similarly, parents wished that the Zambian transport sector, mainly the road and aviation sectors, would enact an ASD child-friendly travelling policy. One father had this concern:

We have been thinking of travelling with our child. We can't go by air anywhere because we know he avoids confined places The minimum of waiting is one hour. You know very well these children, one hour is like ten hours. (Parents: FGD5 P2).

5.10.2 The urgency for affirmative action on existing policies

Policymakers had observed the important role played by the Government to promote disability issues through enacting various disability laws. However, the Zambian Agency for the Person with Disability (ZAPD) felt that Zambia had enough policies and that what it lacked was affirmative action on how to implement the existing policies.

...Yeah... I would start by saying that the Zambian government has demonstrated a lot of political will towards all categories of disabilities through the pieces of legislative and legal frameworks. This Act (Disability Act) does not discriminate against any category of disability. It is inclusive, and the government dreams that everybody is catered for through this Act. Now it faces challenges of financial constraints when it comes to implementation. We are trying a lot to ensure that this dream is realised. The financial constraints have been a challenge and I think for the Government to overcome this problem, they need to increase the budgetary allocation to disability issues because it is too insignificant. If you look at the budget allocated to disability in this country, it is insignificant. (Professional: LPM1 PP9).

A professional from ZAPD had this conclusion regarding policies on disabilities:

I think the policy is clear on all categories with disabilities. It's a question of pushing it, implementing. Drafting a policy is one thing and implementation is another. (Professional: LPM1 PP9).

Theme 3 revealed the inadequacy in ASD policy development and implementation. This had been caused by the lack of specific ASD policy frameworks and the failure by the stakeholders to implement the existing disability policies effectively and efficiently.

5.11 Summary of the chapter

Three themes emerged in this study that illustrated the barriers faced by parents in accessing quality support services. Theme 1 highlighted how parents moved from one service provider to another multiple times as they sought the services needed. Parents had to seek the services of medical professionals, traditional healers and religious leaders, services which they described as being unsatisfactory and depressing. The key observation was that all the three service providers had limited understanding of what ASD was, its causes, diagnosis, and treatment. Each service provider had their own understanding of the cause and treatment of ASD. This frustrated parents.

Theme 2 on community and informal support has discussed the need for parents to access social and emotional support from the family members, the community, and other stakeholders. However, parents faced barriers and felt hindered in their efforts to access informal support services. The community discriminated against them and their child, and there was a limited number of parent-led support groups to help and support them. This was because parents lived isolated lives.

Finally, Theme 3 on ASD specific knowledge and formal services looked at the desire by parents to be capacity built with knowledge and skills on how to manage a child with ASD. Parents wanted to be trained in entrepreneurship so that they could become self-reliant, instead of depending on donors for financial support to meet the child's needs. This was after they had observed that formal social services such as education, health and transport were costly, as they could not afford them with their out-of-pocket money.

In summary, the chapter has identified the nature of the problems that both parents and professionals experienced in accessing ASD services and providing them respectively. Chapter 6 explores the actions taken by the parents to address the prevailing challenges they had encountered.

CHAPTER 6: PARTNERSHIP IN ACTION: RESEARCH FINDINGS ON A PARENT- LED SUPPORT GROUP

The ball is in our hands. Yes, it's overwhelming, it's challenging, but nobody is going to do this work for us. If we don't go out there to create awareness, it is not going to happen. It will reach 100 years and will still be saying the same thing and people will continue hiding their children in their homes. (Parent: MM3 P3).

6.0 Overview

The participatory action research (PAR) actively engaged parents to address challenges affecting them in their local environment. In Phase two only professionals whose services were needed by the parents were invited. These professionals were only invited at the request of parents during action cycles. Most of the activities in the action cycles were done by parents.

The goal of PAR was to link practice and ideas in the area of human development (Reason & Bradbury, 2008). PAR was built on the premise of connecting research with action (Stringer, 2014). The quote above (Parent: MM3 P3) summarised the ideas which were generated by parents and professionals during the research process.

This chapter explores the empowerment process of 17 parents. The chapter is divided into two sections. The first section presents an inventory of action learning meetings that parents had in different communities, in both rural and urban settings, and how they fit in the action cycles that are described in the next section. Section two describes the implementation of the five inter-linked action cycles that emerged from the meetings. The five action cycles are:

- Formation of a parent-led support group
- An advocacy and communication meeting in higher institutions of learning
- A participatory workshop for both parents and professionals
- Rural community mobilisation
- Publishing of stories and taking the advocacy messages to the broader community

6.1 Recruitment of parents

As discussed in Chapter 4, parents in Phase two were recruited among those who participated in Phase one and volunteered to continue with Phase two. Only 17 parents, three men and 14 women volunteered to continue with the study.

The highest levels of education were tertiary education. Seven parents had tertiary education, four had Grade 10-12, One parent had Grade 8-9 qualification and five had Grade 1 to 7 qualification or never went to school. Nine parents came from rural setting whilst eight were from the urban setting. See

Table 6.0 showing biodata summary of participants in Phase 2.

Sex	Age	Status	Location	Qualification			Occupation	Child's date of birth
				Participant	Spouse	Current Studies	Participant	
F	49	M	Urban	Grade 8-9	Grade 8-9	N/A	Housewife	28/09/08
F	42	D	Rural	Grade 10-12	N/A	N/A	Marketer	19/02/10
F	36	M	Rural	Grade 1-7	Grade 10-12	Grade 10-12	Housewife	30/09/04
F	48	M	Rural	Grade 1-7	Grade 10-12	N/A	Marketer	20/08/09
F	77	W	Urban	Standard 6	N/A	N/A	Retired	30/03/09
F	53	M	Urban	Grade 10-12	Never Went to School	N/A	Marketer	2016
F	48	M	Urban	Never went To School	Grade 1-7	N/A	Housewife	24/04/2004
F	42	S	Urban	College	N/A	N/A	GRZ Worker	30/04/2007
F		M	Rural	Grade 10-12	Grade 10-12	N/A	Home Business	16/07/2011

F	29	S	Rural	College	N/A	No	Agriculturists	23/05/06
F	34	M	Rural	Grade 10-12	Grade 8-9	Yes	Marketer	1/02/06
F	48	D	Rural	Grade 1- 7	N/A	No	Trader	13/03/06
F	28	O	Rural	University	N/A	No	Un employed	13/07/04
F		M	Urban	University	University		Teacher	22/11/2009
F	36	M	Rural	University	University	No	Lecturer	2015
M		M	Urban	Certificate		No	Assistance Finance Manager	2015
M	45	M	Urban	college	University	Yes	Forest officer	15/01/07

Key

M=Married

O=Others

W=Widow

S=Single

D=Divorced

Parents were involved in five action cycles. Action cycles are ‘messy’, and it is not easy to say where one cycle begins, and the other ends as stated in the methodology chapter (chapter four). In action cycle 1, parents formed an informal support group and elected its leadership. The goal of forming a support group was to work as a team and use the power of a group to influence change in the communities. Action cycle 2, parents advocated and communicated ASD messages to higher institutions of learning. The next action cycle parents conducted participatory workshop which involved teachers, fellow parents, and ASD professional experts. After this, the next action cycle was the support group took the awareness message to rural community where they conducted rural community mobilisation. The last action cycle was the idea of publishing their stories in the media and taking the advocacy messages to the broader community.

The challenge in writing this chapter was that cycles of action in research did not tend to evolve in a neat sequential process, but as a messy process with concurrent cycles influencing each other (McNiff, 2002). In reporting on these cycles, participants' active voices (quotes) have been *italicised*.

6.3 Section One: Action learning and reflective meetings in both rural and urban settings

In this section, I highlighted a few reflective and action learning meetings that took place between the action cycles. The parents and the researcher worked together, and I was a co-learner during the meetings. During the reflective and action learning meetings, parents learned concepts of planning, acting, evaluation and reflection. To achieve this, the content of the meetings was based on Lorenzo's (2005) questions:

- i. What is it that we planned to do? When and how?
- ii. Did we achieve our goal? What were the challenges we faced?
- iii. Are there changes that we saw and what lesson did we learn?
- iv. What is our next step of action? Who will be responsible?
- v. When do we take an action? How do we do it?

Lorenzo's (2005) questions became a checklist, which was used to focus on reflection on each activity, evaluate the success of the activity and determine the next steps of action to be taken. Table 6.1 describes the meetings conducted and how they are linked to action cycles.

Table 6.1: Description of action learning meetings

Number of meetings	Date	Action cycle	Venue	Activities and matters raised
One	23/07/18	I	Curriculum Development Centre (CDC)	▪ Parents planned to form a parent-led support group. ▪ Parents planned for advocacy meetings with professionals. ▪ Parents elected its leadership to help coordinate activities. ▪ Participants explored issues of logistics and administration of activities during phase two.
Two	30/08/18	2	Natural Resource Development College (NRDC)	▪ Parents conducted an advocacy and communication meeting with professionals. ▪ Mothers spread advocacy and communication information to professionals.
Three	7/09/ 2018	2	CDC	▪ Parents conducted a meeting to evaluate the lessons learned during the NRDC meeting. ▪ Parents planned to conduct a one-day workshop which would include parents themselves and professionals. ▪ Parents planned to publish their stories in newspapers. ▪ Parents planned to engage in an online group meeting to share their experiences and for communication purposes.
Four	13/09.2018	3	Bauleni Special School Conference Hall	▪ Parents conducted a capacity building workshop with professionals and parents. ▪ Parents organised a one-day workshop to train both professionals and parents themselves about ASD.

				Participants conducted a planning meeting to visit Chilanga rural district through the WhatsApp group.
Five	21/09/18	4	Namalombe Primary School	- Parents mobilise the community and take advocacy and communication messages to rural communities. - Parents conducted an advocacy meeting for parents of children with ASD and the general rural community in the Chilanga district.
		5	Not applicable	Publishing the stories: - Parents agreed to publish their stories in newspapers to increase the readership and awareness messages. - Two stories were published in private and public media.
Six	5/10/2018	5	CDC	- Parents reflected on the sustainability of the project. - Parents conducted a reflective meeting on Chilanga rural district meeting. - Parents reflected and gave feedback on the lessons learned during the whole phase 2 activities.

Table 6.1: Detailed description of the outcomes of the meetings

6.4 Section two: Parents' empowerment action cycles

This section gives details on how parents took action to address the barriers to ASD support services. The reflective and action learning meeting above led to the formation of five action cycles and followed the four principles of Plan, Act, Observe, Reflect (Kemmis & McTaggart, 1988)]. The four action steps of PAR are, viz:

1. **Plan:** Parents developed a plan to mitigate the challenge identified. The plan aimed to improve what was already happening.
2. **Act:** Parents took action to circumvent the barriers and hindrances to the availability of ASD services.

3. **Observe:** Parents observed the effects of action in the context in which they happened.
4. **Reflect:** Parents reflected on the effects of the action and used them as a basis for further planning.

Figure 6.1 illustrates the action cycles that were developed during the meetings in various areas. Each action cycle represents a sub-section of the action participants took to address the phenomenon affecting them.



Figure 6-1: Empowering action cycle

The main challenge that parents faced before the action cycles were conducted that needed to be addressed was the lack of empowerment skills and knowledge by parents to make them act on challenges affecting them in the community. It is in this section that I explained how parents empowered each other and promoted ASD awareness in both urban and rural settings. The use of action cycles generated many benefits to parents as shown in the table 6.2.

Table 6.2: Summary of Action Cycles benefits to parent’s support groups

ACTION CYCLE	PRE-LEARNING	POST-LEARNING
ACTION CYCLE 1 Parents form a support group	Parents had limited knowledge and courage on how to come together and form a support group. Each parent was advocating alone, and some parents could not even advocate for their child with ASD	Parents managed to form a support group. The benefits included, sharing their knowledge and skills about ASD. The support group was used as a channel to reduce stress, share lived experiences, get advice and counselling from fellow parents. Parents found comfort in the group as offered by fellow parents.
ACTION CYCLE 2. Parents conduct an awareness meeting at NRDC	Parents had a wrong perception about professionals in higher learning institutions. They felt that all professionals had knowledge about ASD.	Parents were able to dialogue with professionals and took the ASD awareness message to higher learning organisations. Parents learned the skill of how to dialogue with professionals.
ACTION CYCLE 3 Parents conduct a parents, teachers, and	Before the workshop, there was limited collaboration between parents and professionals.	Parents were able to collaborate and share their challenges with professionals.

community capacity workshop.	Parents underestimated the value of using local games and materials to enhance behaviour management in ASD children.	Parents learned how to use local games to enhance behaviour management in children and appreciate local materials and games Parents were able to negotiate power imbalances with professionals.
	Parents had limited knowledge on developmental milestones of a typically developing child and those with ASD.	Parents learned the benefits of having knowledge about developmental milestones as it assisted them to identify services that the child may need at an early stage of the condition.
ACTION CYCLE 4 Parents conduct an advocacy meeting in rural	Parents could hardly think of how best to take the awareness message to rural community.	Parents were able to share their lived stories, distribute materials on ASD. Parents were able to share the knowledge they acquired from professionals with the rural community.
ACTION CYCLE 5 Parents published their stories in newspapers	There was limited publication to the wider community about ASD	Information about ASD reached a wider community by publishing their stories in the media.

6.5. Action Cycle 1: Formation of a parent-led support group

Upon realising what the barriers to the unmet needs of their children were, parents decided to form a parent-led support group, and the following steps were followed:

6.5.1 Plans: The significance of forming a parent-led support group

Parents came together and formed face-to-face and online support groups intending to identify common goals and weaknesses. During the planning meeting, parents became aware that an informal parent-led support group (PLSG) would help reduce uncoordinated activities and the dependence on the facilitator to lead the activities. Furthermore, a parent-led support group would help parents share their lived experiences of ASD support services in Zambia.

Considering that this was the first meeting of the PAR process, an explanation of the objectives of Phase 2 and its activities was given by the researcher. An agenda was drafted and modified by the parents. The final adopted agenda was as follows:

- Prioritising barriers and addressing them.
- Organising transport and project funding.
- Days of meeting and venues.
- Modes of communication and strategies thereof for the parent-led support group (PLSG).
- Selecting an institution of higher learning for an awareness meeting.

At the first planning meeting, parents agreed to prioritise advocacy and communication, as well as parent and professional capacity building. Advocacy and communication were highlighted because of the low understanding and awareness of ASD by the society. One parent observed: *They don't know about ASD, but general disabilities. Therefore, there is a need to talk about ASD specifically* (Parent: MM1 P10).

Another activity that parents first planned was the issue of transport during community awareness activities. To facilitate transport to meetings and activities, five parents who owned vehicles and the researcher agreed to provide lifts to others. The chairperson of the parent-led support group contributed some funds towards transport for rural and township parents: *I have contributed a K500 towards transport* (Parent: MM1 P4). Parents agreed to meet twice a month, from 10 a.m. to 12 p.m. However, the meeting days were flexible. The proposed venue was the

Curriculum Development Centre (CDC) in the Lusaka District because it was safe and easy to locate. The venue was provided to the researcher for free since the researcher was one of the members of staff within the Ministry. The group agreed to form a social media support group (WhatsApp). The secretary was tasked to collect the names of all participants and create a new group for families of children with ASD. This group was used for decision-making and the sharing of information. However, parents who were not able to join the online support group were always updated of what was discussed or posted on the group regarding any activity.

The consultations amongst parents in the parent-led support group resulted in the group designing specific programmes that needed to be addressed. The first suggested activity was to conduct advocacy and avail communication messages to densely populated areas in townships:

In the township where I stay, there are many children with ASD who are taken care of by Cheshire Homes, a non-governmental organisation. The Cheshire Homegroup usually visits our Catholic Church in Chipata Compound (township). I can talk to the priest to invite all parents of children with ASD who works with Cheshire Homes. I know this can work and we can talk to the parents. (Parent: MM1 P12).

The probable reasons for first selecting townships were that the areas had higher populations and the majority had insufficient information about ASD because of low education or limited access to ASD resources. Even though the meeting was exclusively for parents, one special education teacher who participated in the Phase one interviews accompanied the participants to the meeting, because some parents did not know where the venue of the meeting was. The professional took advantage of the meeting to submit to the parents:

In my rural area, we have over 5000 households. We have children with ASD, and parents are still in denial. They hide their children in car garages. They don't allow children with ASD to come outside. This is happening in the houses... Very few parents have come out in the open to say that I have a child with ASD. I am a special education teacher.

There, most of the parents keep their children in their homes....
(Professional, Teacher).

The information from this teacher alerted parents on the need to take awareness messages to rural areas too. As the first planning meeting was going on, all the parents expressed their opinions regarding the choice and schedule of events. Other parents suggested that they first target media houses before working on community ASD awareness messages. However, it was observed by the parents that dealing with the media was a costly venture: *I think the media would be expensive because they need money to air programmes* (Parents: MM1 P4). After the parents had debated at length among themselves on which place and activity to visit and do first, they decided to settle for higher learning institutions. This was justified in four ways. One of the reasons brought forward was that professionals were among the key stakeholders in Zambia who had a greater influence on how policies are enacted. The other reason was that professionals are a bridge between the masses and policy implementers when it came to issues of advocacy and social change. The third justification was that the students and staff from higher institutions of learning are well respected and were regarded as the source of ASD knowledge in their respective communities. Lastly, it was argued that ASD information could be incorporated into the curriculum and coursework in higher learning institutions. The above justification resulted in parents to agree that the first meeting was going to be conducted among professionals in institutions of learning. During the planning process, parents agreed to involve their children with ASD as part of the advocacy group. I heard one mother suggesting to the group:

... I think we need to go with children with special education needs from the University Teaching Hospital School. These children can go and recite poems as part of the awareness programme. (Parent: MM1 P10).

Parents agreed that children with disabilities should be included as advocates, mostly those who could express themselves. Parents observed that, in most cases, children with ASD were sidelined in advocacy activities despite being the ones most affected. The parents' idea to engage their children in the ASD awareness programme was born after one parent had witnessed

children with disabilities reciting thought-provoking poems at school. Part of the poem she heard and recited read:

Don't look down on us, we are also human.

We also feel pain if bitten by a mosquito

We feel the pain when the sun is shining hot

We also feel pain when we are sick

We feel it....

We are normal people like you. (Parent: MM1 P10).

After listening to the content of the message in the poem, parents were excited and agreed to involve their children with disabilities in the advocacy and awareness programmes. Parents were informed about the need for the informed consent of the participating children. Parents consented to the researcher's suggestion. The planning meeting culminated in an action plan as discussed below.

6.5.2 Action: Electing the leadership

Parents saw it prudent to choose their leaders and establish an informal support group. As a facilitator, I did not want to restrain the group from exploring avenues of using their lived experiences and the power to exercise their rights to choose the activities, how to execute and implement them. Parents voiced their views by deciding to elect their leaders on their own. Three names were proposed for the position of the chairperson: Parent MM1 P1 suggested: *I propose parent MM1 P4 to become our chairperson and the vice should be Madam MM1 P7.* However, parent MM1 P7 said that she was not ready to be vice-chairperson but a secretary: *I think I can take up the role of secretary (Parent: MM1 P7).* The name of Parent: MM1 P10 was also proposed for the position of chairperson. The group agreed that the one who gets more votes becomes the chairperson and the runner-up the vice-chairperson.

Parent MM1 P7 went unopposed for the position of secretary since she had earlier shown interest and volunteered. Thus, a three-member executive committee was democratically elected, comprising the chairperson, vice-chairperson and secretary. The final support group

consisted of 17 parents, two males and seven females from an urban setting and one male and seven females from rural areas.

As part of the group ethics, parents agreed to keep confidentiality on issues to be discussed and allow freedom of expression and the respect of everyone. Guidelines on issues of group membership and conduct during meetings were set. In addition, each member was given a printed copy of the guidelines. Parents were requested to sign in a register each time we had a meeting (see appendix R).

6.5.3 Observation: We need to target the local community

The parent-led support group observed that many people in their local communities did not have adequate information about ASD. The parents' objective was to first take advocacy messages to the immediate members in their communities before going to remote places: *I think we need to target those people we interact with daily in the community. After this, we can go to the wider population* (Parent: MM1 P5). Parents felt that the local community members were in the majority and were the ones who might not be aware of ASD.

6.5.4 Reflection & learning: How we see our world

Parents participated in reflection learning activities such as the writing of poems and brainstorming activities. A reflective and learning meeting was conducted by the parents. Questions for reflection included: Who is involved in the formation of the support group? Whose benefit does it serve? What were the barriers to the planned activities? How do we reduce on the barriers in ASD services? The feedback from the questions came in form of a poem: As part of reflection, parents were involved in a poem. The poem was written in pairs. The focus of the poem was about how as a group they could advocate for a better world for child with ASD. Parents developed the poem below.

We See Our World

- *We see our world that is inclusive where we no longer must explain the condition of the child because everyone knows about it, understands, and accepts it.*
 - *We see a situation where our children do not hold back on anything because they are catered for by society.*
 - *We see our children fully integrated into society and utilising their full potential.*
 - *We see ourselves as advocates for our children, pillars of hope, and sources of protection*
 - *We see ourselves as agents of change and show the world that diversity is inevitable. Different flowers are what makes the garden beautiful.*
 - *We see ourselves and we are alive to the fact that what people take for granted as a child's daily routine are our daily struggles.*
- We will use all our available resources to help our children reach the highest potential.*

Figure 6.2 : A poem developed by parents on the future they dream of for their children

However, there were some oversights in the composition of the parent-led support group executive committee. It was realised that all the elected members in the executive came from the urban setting. We could have done better to have a balanced executive committee, with representation from both rural and urban areas. However, parents from rural areas and township settings participated in the election of the executive. Maybe these parents might have developed an inferiority complex towards the leadership because they could not contribute financial resources to the same extent that urban parents could. However, since the executive committee was democratically elected in line with PAR principles, there was no tension observed from the group during the activities.

6.6 Action Cycle 2: Taking ASD awareness to higher institutions of learning

Parents explored the importance of promoting awareness in higher learning institutions. During the action cycle, the following activities were done.

6.6.1 Plans: We can go to higher learning institutions

In Zambia, academics are considered as the bridge between the community and policy makers in knowledge dissemination and influencing policy formulation. Parents were ready to raise ASD awareness. The formation of a parent-led support group acted as a pressure group to advocate for social change in the community. The group planned to talk to both members of staff and students for an hour only. The secretary of the parent support group made this suggestion: *I think, I can write the letter to NRDC so that we talk to members of staff or students* (Parent: MM1 P7). Parents were eager to campaign against ASD discrimination in the quickest time: *Can it happen so soon?* (Parent: MM1 P10). The secretary said: *I can draft the letter today and take it tomorrow and this will help us to know the tentative date when we may have our meeting. I will give the feedback by tomorrow* (Parent: MM1 P7). Parents finally agreed to take the ASD advocacy information to NRDC: *I think NRDC can be the first one* (Parent: MM1 P10). NRDC was selected because the secretary of the parent-led support group was a former student who had faced academic challenges, both as a student and as a mother of a child with ASD. Secondly, parents were confident that participants would be more receptive to the ASD awareness messages when they saw one of their former students advocating for ASD awareness. Thirdly, parents felt that they would easily be welcomed at NRDC because the head of the institution had some knowledge of ASD:

I think the principal has at one time worked with children with ASD before and maybe she can allow us to go there. I hear that in their curriculum, they have started incorporating disability studies. Something like that.... (Parent: MM1 P7).

Building from the lessons learned during the planning stage, parents agreed to take action to address issues of advocacy and communication within the context of higher institutions of learning.

6.6.2 Action: Being a parent of a child with an “invisible disability” is a lonely journey

Six women visited Natural Resources Development College on the 30th of August 2018. The main agenda of the meeting was to promote ASD awareness and to inform the NRDC staff that raising a child with ASD could be a lonely journey without support from the community. Parents acted by promoting ASD advocacy among members of staff at NRDC, using various

strategies. The advocacy and communication approach gave the parent-led support group power to make choices, express opinions and make decisions on identified barriers to support services. The outcome was that parents developed observable self-esteem and freedom of expression and opinions. Using advocacy skills, parents of children with ASD were able to speak out for themselves on the challenges they faced in raising their children and managing their behaviours as they sought formal and informal support services. Through communication, parents were mindful that any successful advocacy programme would depend on the strategies used important messages being communicated by the group to the community. The goal of using different strategies was to improve the professionals' understanding of ASD.

6.6.2.1 Strategy one: Parent narrative-centred approach

Parents narrated their stories to the professionals at NRDC. Four parents explained what it meant to be a parent of a child with ASD. During this period, participants listened to the parents' lived experiences. To win the confidence of the participants, before narrating their stories, parents introduced themselves and explained the agenda of the meeting:

We are just parents who have met because of this condition called autism and we are going around to try to sensitise you people as much as we can. This is because it is not only children who have autism but even adults living in our communities have but may not be aware that they have the condition. (Parent: FGD9 P1).

By first introducing themselves, they were connecting themselves to members of staff. Parents knew their goals and what they needed to achieve by the end of the meeting. Mothers who could not express themselves in English did not shy away from sharing their experiences in local languages: *My name is MM2 P5, Nizakambako mu Cinyanja (I will use Nyanja to express myself) (Parent: MM2 P5).* This was despite a negative perception and inferiority complex among the Zambian society where people who could not express themselves in English are less educated than people who could converse in English. Professionals listened to parents' experiences in the local language: *No problem, go ahead.* Said one professional. One mother from a township who spoke in local language explained how she suffered discrimination together with her child in the township because of having a child with ASD. She had the following advice to the participants in the meeting: *My advice to all of you is that these children*

with autism need to be loved, otherwise if you don't treat them well, they will isolate themselves as they feel bad (Parent: MM2 P5). Another mother highlighted the misconception surrounding a child with ASD:

There is a lot of misconception and a lot of things come in because sometimes it's difficult to interact with these children who have what I call 'invisible disabilities'.... You see this child starts throwing tantrums, screaming, hitting his head and you think maybe this child has been bewitched or he has demons and needs deliverance. (Parent one: MM2 P1).

One mother narrated to professionals some of the early symptoms of ASD. She explained that many parents including doctors hardly associate such health conditions to ASD: *He started developing stomach problems, he was constipated for a long time and then he developed diarrhoea and I was in and out of the hospital and they didn't know what was causing that* (Parent two: MM2 P4).

6.6.2.2 Strategy two: Practical demonstrations

Parents brought a child with ASD to the meeting to show participants what it meant to have a child with ASD and the burden of raising such a child.

I have come with my son, because most of the time when we talk about autism, I have realised that it's very easy for people to say, oh yeah, autism, autism, but not until they interact with them that is when you hear them say; 'OH, so this is what you were talking about.... This is one of the things how autism looks like. This is the child, when you look at him, he is able-bodied, and well physically developed. He will probably not look into your eyes. He will grab things. (Parent: MM2 P1).

This practical experience of being able to observe a child with ASD increased the levels of attention amongst members of staff because most of the participants were seeing a child with ASD for the first time.

The promotion of ASD advocacy was not only done by primary caregivers (Biological parents) but even secondary caregivers such as aunties who wanted their voices to be heard in the community. One secondary caregiver narrated:

I don't have a child with autism, but my sister does. That means that my children will have to grow up with their brother who has had autism all their life. So, if I teach my children about autism, it becomes easier for us to grow in a community that is aware of autism. (Parent: MM2 P3).

The two stories above received more reaction from participants who wanted to know more about ASD and how to promote ASD awareness in their communities. This led to a question-and-answer session, which used a parent-participant centred approach.

6.6.6.3 Strategy three: Facilitating a question-and-answer session

The parent-professional approach took the form of question-and-answer dialogue. Parents allowed members of staff to ask questions regarding ASD, its causes, diagnosis, and treatment. This approach allowed professionals to open and ask pertinent questions regarding ASD. One professional woman asked the following questions:

I am very grateful for this topic, very enlightening. I appreciate it. I wanted to ask (Parent: MM2 P3). You said your sister has a child with ASD and people shun such children? I have seen a situation where a relation or a family member has a child with autism, but it was never discussed. I now know much about ASD maybe because I could tell from the child's behaviours. How do you talk about a child or help a family that has an autistic child and yet they don't open to the family members or extended members? (Female, Professional: August 2018).

In response to the question, parents gave the following advice to the participants:

I think perseverance, autism is just like any other disability, and I know there was supposed to be a talk about HIV Test here. Sorry for that. HIV is something we don't like to discuss. If I'm affected and am in denial, I don't want somebody to know about it, or take medicine and

all those things. But maybe because of the challenges that I will go through, people will keep coming and talking to me about accepting, about taking medicine, that perseverance is what will help drive me to eventually go for the test and start taking the medication. I think it is the same that applies to autism, if you see that people are resistant, try to use different channels to reach out to them and talk to them. If you see that it's difficult, bring somebody else like an expert. The same way we deal with other cases is the same way we need to deal with autism (Parent: MM2 P3).

*...you know what makes people not be open? It's because of the way society looks at children with autism. I will talk of my personal experiences; when my child was born, being the first child, I did not know what autism was. My child could fall sick at any time; maybe being at work, you will just receive a phone call that the child is sick. I had no experience, and it was my first time had many challenges. At times I could go with my child to work to get permission from my bosses and then the other women would say: **Uyu mwana sibanamupeleke ku malo** (The child was not traditionally cleansed) As a result, parents try to close up due to the way society perceives children with autism. (Parent: MM2 P6).*

The two parents' responses above illustrated the need for the community to be aware of ASD and take a leading role in social change about ASD. The first response highlighted the good lessons that could be adapted from HIV/AIDS campaigns to ASD campaign messages to reduce ASD stigma. In the second response, parents highlighted the importance of the community having a positive attitude towards people with disabilities and their families. The interactive dialogue between parents and professionals inspired one male professional to ask:

Do you have a support group or where you are found? In case I come across a child with autism. Do you have a brochure or something like that? (Male, Professional: August 2018).

This was interesting to see fathers asking such questions because childcare for children with disability is generally viewed as women's work in the Zambian culture. The question by a male professional resulted in total silence in the room. I could see the hesitancy from the parents to stand up and answer the question. This was because they realised the lack of existing formal and informal support services. One parent gathered courage, walked in front, and said:

Now what we can say is we are only a group of parents that have come together, and we want to form a council, like the Aids Council of Zambia, for autism. We have a support group as parents; we support each other to exchange notes. We have started with autism awareness as we are waiting to come up with that council.... We want Zambia to be also on the map that children with autism are also excelling in Zambia. We hope our visit here will raise awareness and help at least bring out more children from out there to be diagnosed and get some early intervention. (Parent: MM2 P4).

After the meeting, one parent said: *I did well to come, I have also learned a lot during the meeting.* Such sentiments from parents showed that parents appreciated the meeting and acknowledged that they learnt as much as they shared.

6.6.3 Observations

The initial plan of the meeting was to talk to both members of staff and students. However, parents only managed to talk to professionals because the students were preparing for examinations. Parents realised the potential they had in themselves to talk in public. Parents were very confident that they had promoted social change among the professionals who were then aware of ASD: *We hope our visit here will raise awareness and help at least bring out more children from out there to be diagnosed and get some early intervention. (Parent: MM2 P4).* Parents observed that the use of different strategies during the dialogue was beneficial to both them and the participants as it inspired the participants to ask questions regarding childcare and the causes of ASD. NRDC staff became more interested in the discussion when they saw a child with ASD, and this helped them see the reality of what it meant to be a parent of a child with ASD. The campaign about ASD did not only highlight the burdens of having a child with ASD but also educated the participants about the need to know and understand that ASD did

not only affect an individual in childhood but also adulthood. The campaign was not only about their little children but for all persons with ASD: *Not only children who have autism but even adults* (Parent: FGD9 P1). These observations by parents led to the next stage of planning.

6.6.4 Reflection and learning: Professionals as novices of ASD

After conducting an advocacy meeting at NRDC, parents had a reflection and learning meeting. Parents showed signs of gaining self-confidence on issues of advocacy. Considering that this was the first public presentation that parents conducted, parents had to reflect and evaluate their growing competencies and challenges that emerged during the NRDC meeting. I asked the participants to mention some of the lessons learned during the meetings.

Researcher: What were some of the challenges that you observed?

6.6.4.1. Lessons learned: Low knowledge and understanding of ASD among members of staff in higher institutions of learning

During the reflection meeting, parents realised that most of the staff who were present had limited knowledge of ASD. One parent had this say: *The first challenge was that most of the participants did not know anything about ASD* (Parent: MM3 P3). The lesson learned was that it was not every member of staff at NRDC who knew ASD. Parents might have assumed that members of staff knew about disabilities such as ASD which they thought was incorporated in their curriculum.

We discovered and confirmed that in Zambia, the understanding of ASD was still low in society and even among members of staff in higher learning institutions:

A lot of people don't know about autism. When I started the presentation, I asked them if they knew what autism was. Only one member of staff of the over 20 participants knew what autism is. He learned of it from the neighbours who had a child with autism. This was after asking his neighbours about the child's condition which looked strange. (Parent: MM3 P3).

Parents saw the need to continue with the campaign on ASD after learning that most of the professionals had limited knowledge of ASD.

6.6.4.2. Benefits of using variation in dialogue techniques

It was critical to use various techniques, such as the use of visual aids and practical demonstrations, to show the participants the actual child with ASD. These approaches provided beneficial information to NRDC members who had limited knowledge and understanding of ASD. Such strategies stimulated their attention.

After the interaction, you could see that it was an eye-opener for them. They asked a lot of questions. They understood and in fact, we took a step further and we went with a child because some think there is somewhere where it is written that this child has autism. We showed them how an autistic child looks like and told them how to manage and care for children with autism.... (Parent: MM3 P3).

Despite parents employing different methods during the meetings, they acknowledged some gaps in their presentation, considering that this was their first public meeting as a parent-led support group: *The second weakness was that I think as parents we did not adequately prepare, maybe we needed to show a video and distribute some handouts on autism (Parent: MM3 P3).*

6.6.4.3 Time management and resiliency

Parents managed to arrive on time for the meeting. However, the meeting did not start on time as there was another meeting in the venue that had been assigned to them. The support group secretary had this to say: *When we reached NRDC, we found that there were three meetings and at the same time we were supposed to hold our meeting, we had to delay a little bit. We later had our meeting. (Parent: MM3 P3).* Despite the meeting starting late, parents showed resilience by not leaving before the meeting could start. They had to wait for over two hours before the meeting could start. Parents had planned to have a one hour talk with the professionals. The meeting went beyond the proposed one hour: The secretary observed: *Time Management? We did not manage our time well (Parent: MM3 P3).* The programme went beyond the time that was suggested. This was because parents had a lot to share with the professionals within a short time. Though the meeting started late, it attracted a lot of questions and parents wanted to address the ‘thorny’ issues that professionals wanted to know about ASD. As part of reflection, parents used symbolic drawings to depict their strengths and challenges as they sought awareness for ASD.

It was during the reflection and learning session that parents identified their own inadequacies about ASD and childcare and some limited knowledge about ASD among professionals. This prompted parents to think of conducting a participatory training workshop involving both professionals and parents themselves. This led to Action Cycle 3.

6.7 Action Cycle 3: Parent-professional partnership

Parents had to organise a workshop where they partnered with teachers. The goal of the parent-professional partnership was to get empowered and negotiate some imbalances on issues they had limited information. The first task was to plan activities.

6.7.1 Plans: Participatory workshop

Action Cycle 3 involved the action taken by parents of conducting a one-day workshop in partnership with Mulenga Autism Foundation. The aim was to build capacity in themselves and special education teachers. The targeted number of teachers was 60-100. The proposed venue was Bauleni Special School conference room. Professional experts to facilitate the group were invited by Mulenga Autism Foundation, who organised and funded the meeting in partnership with parents.

This planning meeting was based on a needs-based approach. This was because parents and professionals required adequate knowledge on how to educate a child with ASD using local materials. Both parents and professionals wanted to find best ways in which they could collaborate as they engaged in educating a child with ASD. It was for this reason that the experts invited were based on parents' needs and experts' experiences of working with ASD children. The planning for this workshop was done during the reflection meeting which was held on 7/09/2018 at the Curriculum Development Centre. Parents planned to invite professionals and other parents of children with ASD who were not part of study.

6.7.2 Action: Enlisting for support

A one-day participatory workshop was conducted, running from 9:30 to 17:00 with 40 parents (20 parents of children with ASD). The number of professionals from special schools in the Lusaka District was 12. One parent from the parent-led support group was one of the key presenters. During the training workshop, parents participated in various activities, which included demonstrations on how to play with the child, games and dances, plenary sessions, and group discussions.



Figure 6.3 : Photos of the parent-led support group

The photos of the parent-led support group and participants during action cycles in Figure 6-3 are as follows from left to right: The special education teachers having a group discussion, next is the research assistant Henry giving instructions to participants and the bottom photos are the two workshop facilitators during their presentations. The far-right is one of the mothers of a child with ASD who was part of the parent-led support group (used with permission).

The topics of discussion during the workshop included the following:

- Understanding the developmental niche (pathway) for both the child with ASD and the typically developing child.
- Understanding common cultural myths about ASD and child development.
- Respecting the child's space in the environment.
- Using local materials to enhance communication and behavioural skills.

6.7.2.1 Topic 1: Understanding the developmental pathways

Parents and teachers were involved in various activities. All parents needed to have knowledge about the developmental pathways for both the typically and atypically developing children. The information was critical as this would help both parents and professionals know how to assess a child with ASD. The first facilitator, a parent from the parent-led support group, explained how a child developed: *Development is gradual and we don't see it and so even for our children with special needs.... It's cumulative. It is relatively permanent.* Parents: MM4:P1).

She explained that not all children grow at the same time including children with disabilities: *We are not all going to develop at the same time. So even children with special needs, grow differently.* The presenter urged parents to appreciate children with ASD because they are many lessons which parents and the community can learn from children with ASD as they grow and interact with their environment. She said: *What the child brings to the environment is as important as what he takes from the environment. Children have ideas and we need to respect their preferences... Attachment is very important to the child.* She further encouraged parents understand the developmental pathways of children, as each child's developmental niche is unique. The presenter also said that each child requires secure attachment from the capable others such as parents and older siblings: *You need to develop an emotional bond between a parent and the child. This helps the child to explore the world and within the attachment relationship, you see more growth in a child.* (Parents: MM4:P1).

The topic above was critical to parents as it eliminated some myths and fear that the community have regarding children with disabilities. The community may think that children with disabilities such as ASD don't bring any value and experiences to their environment and do not need any parental attachment and bonding with both parents and the peers. This was because there is also a myth that children with ASD condition hardly reach their 5th birthday: *I was told that children with disabilities hardly reach their fifth birthday* (Parents: MM4:P1).

6.7.2.2 Topic 2: Understanding common cultural myths about ASD and child development

The second session was a plenary one and it focused on some common cultural myths that exerted psychological pressure on parents as the child is growing. To stimulate the discussion, the research assistant who was a University of Zambia student was asked by parents to facilitate this session. He asked participants the following questions:

Question one: What are some of the common myths which are perceived to negatively contribute to child development?

Parents dialogued on common cultural myths which were perceived to negatively affect child development. During the discussion, some mothers blamed the men to have negatively contributed to the cause of ASD. This was because mothers felt a lot of younger men have lost respect to health tradition rules and cultural beliefs because they are no longer taught on how to care for a child and marriage initiations:

Men are not taught about cultural and marriage issues and that is a challenge. They just know about giving flowers to the lady. Women are taught about what is needed to keep a marriage. (Parent: MM4 P4).

However, one of the female teachers had a different view. This professional felt that the blame should not only be on men but both couples. She felt that before breaking the health traditional rules and norms, the two couples must reach a consensus:

Modern married couples even have sex when a woman is on a menstrual period. The body is cleaning itself and you go in, you don't know what is coming out and then you go in; these are some of the causes of some diseases (Teacher: MM4: TR 2).

Some parents said that they still followed some cultural advice because they feared being misunderstood and accused of not following cultural norms in the community. Parents had the following observations:

We accept to do some of the cultural demands for fear that should things not happen as I was advised by the relatives; they will all be on me.
(Parent: MM4 P1).

During the dialogue, some participants did not view the quote above as being one of the myths, but as part of traditional education on health. They felt that oral African tradition was the same as scientific medical health advice on how to protect the child and parents from ailments. The difference was that in oral tradition elderly people used proverbs and riddles to explain things. In the African culture, each mother was educated on the need to keep hygiene while caring for the baby. Statements like: *A lady on menstrual period must not touch a newborn baby to avoid diseases*, seemed to oppose Western medical service providers whose emphasis was on childcare, rather than on the mother's knowledge of her hygiene towards a baby who was prone to any disease.

6.7.2.3 Topic 3: The value of the parent-teacher partnership in educating a child with ASD

The next topic of discussion was on how both parents and teachers could educate a child with ASD both at home and at school. The special education facilitator highlighted the importance of having adequate knowledge of how to educate a child in a socially acceptable environment where the child's privacy is respected. This type of knowledge was critical because that was one area parents had a challenge in raising and educating a child with ASD.

We need to learn methods on how to help the child with ASD. For example, if the child does not know how to handle the use of a pencil, give the child an opportunity to learn and do not force them. Consistency is the key to helping the child. Praise the child on each achievement the child makes. Let the child lead the way, respect their space so that they can do their work. (Professional Facilitator: Special educator).

During the presentation, one parent commented: *I did not know about this*. Parents highlighted the scarcity of ASD teaching and learning aids. The training on the use of local resources for speech therapy and behavioural management services sounded like a good idea. The therapist

emphasised the need to use visual aids such as pictures to promote speech development: *You can use pictures. Present the picture with the item. You need to modify the activities and observe the child.* (Professional Facilitator: Speech therapist). She continued by saying that a parent needs to be repeating words with a picture (object) to enhance communication skills in children with ASD:

*The interventions I am talking about can be used at home and school.
How do we help the child with ASD communicate? You need to bridge
the gap by repeating the word and showing the child pictures and
talking to them in their familiar local language.* (Professional expert:
Speech therapist).

6.7.2.4 Observation: Benefits of empowering parents and professionals

Life education skills are a critical component in the lives of children with ASD. This can enable the child with ASD to acquire new knowledge, skills, attitudes, values, and behaviours that could be applied to solve daily life challenges. However, for the child to attain the needed skills, parents, and professionals must be trained on how to care for and raise a child with ASD. Parents observed knowledge gaps both in themselves and in the professionals. Gaining the training in ASD in partnership with special education teachers would reduce gaps in how services were provided to children with ASD, both at home and at school. We observed that the training of parents and professionals as a group would create a cadre of enlightened caregivers who understands the role of both parents and teachers in educating children with ASD. In this respect, parents would become local experts and promote home-based care support services in areas where professionals are hardly found. The outcome of such a programme would improve the health and psychological well-being of parents. This is because some of the parents would become trainers of trainers or coaches for home-based ASD programmes.

The first merit was embedded in a question from one professional in the previous action cycle who asked: *How do you talk about a child or help a family that has an autistic child and yet they don't open up to the family members or extended members?* (Female, Professional: August 2018). The second was born out of observation by parents: *Only one member of staff of the over 20 participants knew what autism is* (Parent: MM3 P3). Parents realised that they could collaborate with professionals through training, and this would influence them to be agents of

change in their learning institutions and society. A parent-professional training programs can have more positive outcomes in promoting quality life for a child. This is because both teachers and parents are the ones who spend more time with the child and are critical key players in the child's development.

It was observed that parent wanted to use the materials that would motivate parents to be ASD advocates. The discussion they had during the workshop informed parents on the type of materials to distribute to rural communities that would assist reduce stigma and discrimination. One of the strategies parents felt would do well was the use of rubber materials. Parents had to use different strategies to increase awareness. Some of the strategies included telling their stories, distributing the rubber materials which had different awareness messages written on them. The awareness message written on the rubber bands could easily be seen and read by many people. Secondly the materials used was durable and could easily be identified by any person when they wear them on. (See Figure 0-1 on page 187).

6.7.3 Reflection and learning: What next after learning?

There were many lessons learned during the training workshop that hosted 40 participants. Group discussions and plenary sessions stimulated discussion amongst the participants. Parents were involved in brainstorming activities, pair work and group activities. The presence of older caregivers (those who were 65-85 years old) in the meeting brought in other dimensions of respecting oral tradition and cultural knowledge as part of traditional education. Older parents informed the group that most of the things we considered as African traditional myths about child development were good lessons with hidden meanings in proverbs and riddles. For example: *the mother should not drink hot tea when pregnant*. The hidden health meaning and warning was that expecting mothers should avoid taking *stimulant substances*, many of which harmed the unborn baby.

Parents learned the need for early intervention programmes for a child with ASD, which included issues such as discipline, and which must be consistent from all caregivers raising a child with ASD:

Development cannot be understood in isolation; at times we are so tolerant that we fail to discipline them. For example, our son has challenges to breaking the routine and you find that whenever it's time to take him to school, it becomes a challenge. The only person who makes him bath nicely and take him to school is the father. If it's me taking him, he will lay down .He is so powerful and at times he refuses to go to school. We don't need to give up, but we need to be sensitive the way of disciplining him. (Parent: MM4:P1).

The early intervention programmes should be the same both at school and at home to avoid conflicts and confusing the child with ASD:

We need to relate the home setting and school to the hospital situation. For example, when doctors tell us to take medicine or they say do this, we follow instructions, so [it] is the same with what teachers tell us. We need a connection between the family and the teacher (Parent: MM4:P1)

Another lesson learned was the use of traditional games to teach skills. Figure 6.4 illustrates parents learning one of the traditional games called **Nkakulele eyaye** (*Let me care for you*). The traditional game teaches motor skills and cognitive development in a child with ASD during play.



Figure 6.4 : Parents demonstrate how they can play with a child

6.7.3.1 Gaps observed during the workshop and pre-planning for the next action cycle

Parents observed that there was more theory work and less practical activities during the presentation by facilitators. The scope of the content was too wide for some parents who had limited education. Parents observed that towards the end of the programme, activities were done in a rush to conclude the planned programme. Participants identified what they needed the most, such as how to teach fine motor skills as advised by the special education teacher who said: *...if the child does not know how to handle a pencil, give that child an opportunity to learn peacefully, do not force them. Consistency is the key to helping the child* (Special education specialist). We observed other shortcomings during the presentation. The experts conducted their lessons mostly in English and a scant mix of local dialects of Cinyanja and Ici-Bemba. This meant that illiterate parents and those who could only read in their own local and familiar languages had a challenge in understanding some scientific terms. However, to mitigate the language barrier, the researcher and research assistants interpreted this into the local familiar languages. All other group discussions were conducted in local languages except the presentations by experts.

6.8 Action Cycle 4: Lift as you rise

In this action cycle I highlight how parents mobilised themselves to take further action in the ASD advocacy to rural communities as a less empowered group of parents and professionals. Parents shared their new knowledge of ASD with others who were less privileged with ASD information.

6.8.1. Plans: All roads lead somewhere

After reflection on the participatory workshop conducted, parents were confident that they were well-trained and ready to teach others more effectively and efficiently. Parents planned to visit rural areas because they felt the need to share the newly acquired knowledge with their fellow parents of children with ASD. The prevailing practice in Zambia concerning service provision favoured parents living in urban Lusaka who have access to therapy services and training in ASD. Parents felt this trend need to change where all roads lead to Lusaka.

The main activities planned were:

- Taking the advocacy and communication information to rural parents.
- Distributing awareness materials to the parents.

The planning of the meeting for Chilanga rural was done through our WhatsApp research group. The use of the online platform proved to be cost-effective for the group as no suitable times could be found to meet face-to-face as a group.

One parent from a rural setting advised the parents to visit Chilanga at the time when the school had an Open-day activity. Parents planned for a meeting on an Open day. Open-day activities in school are programmes that the school organises to showcase what learners were capable of doing. Learners, with the support of teachers normally display to parents' activities like reciting poems, drama, production unit, science, and music projects. Chilanga was targeted because there were stories of parents hiding their children in garages for fear of discrimination.

6.8.2 Action: God has given us these children

On 21st September 2018, six parents from Lusaka visited the Namalombe rural area in Chilanga, about 45 kilometers from Lusaka. We were delayed reaching the rural area because of the heavy traffic congestion due to road construction. Our initial aim was to conduct an interactive

meeting with parents of children with ASD and teachers. However, we discovered that the parents present were coming from various cultural backgrounds. The parents present included those who had a child with other disabilities aside from ASD, parents of children without disabilities, teachers, and community leaders.

Parents (support group) had to quickly adapt to the needs of all participants. We were worried as participants looked fatigued having waited for a long period of time. After the introductions, parents apologised for coming late: *We are sorry we came late, there was a traffic jam in town* (Parent: MM5 P7). Having apologised to the group, parents went straight into the presentation. This was after serving some refreshments to participants. One mother said:

God has given us these children for the purpose so that we show his work through such services. Do not be afraid of your child. If we don't love our children, how are we going to love God whom you have not seen? We can see Jesus through such loving children with ASD. When visitors come, we lock our children in our homes. That is very unfair.
(Parent: MM5 P4).

I observed that the advocacy and communication messages shifted from general to specific. The first target was the general populace, followed by teachers. The parents' advice to teachers was for them to know their roles in the community, that of being civic leaders and agents of change for children with disabilities:

Teachers have a role to play in the community. You need at times visit parents' homes rather than just waiting for them to lock their children in homes or garages. We can help parents by informing them on how to interact with the child rather than locking the child in a garage. (Parent: MM5 P5).

The next specific message was for mothers. Mothers were encouraged to be resilient and develop a positive attitude towards children with ASD: *We as mothers, need to be strong and let us love them, let us care for them and educate them* (Parent: MM5 P4). Fathers were encouraged to be responsible fathers by not rejecting children with disabilities. A great-great-

grandmother who was left with the responsibility of caring for a child with ASD after the death of her granddaughter and the rejection of the child by his father narrated: *The father rejected him because of his condition...* (Parent: MM5 P4).

To consolidate the advocacy and awareness message, parents (who provided the materials), distributed awareness materials to all participants which were donated by Mulenga Autism Foundation. Each participant was given four different coloured rubber wrist bands inscribed with the four messages. The key messages on the rubber rings were: Know autism today (Blue colour); Autism is not contagious (Purple); Neurodiversity (Red); Mulenga Autism Foundation (Yellow) (Figure 6.4). The distribution of rubber wrist bands was to serve as a campaign tool on what ASD was and to spread Autism awareness passively or actively, especially if individuals inquired. Parents felt they needed to use different strategies to reach out to people and advocate for ASD awareness



Figure6.5: Awareness materials distributed to parents as part of an education campaign tool

6.8.3 Observation: We are human, and we can be flexible

During our planning, we targeted only parents of children with ASD. However, we found a mixed group of different parents. Despite that, we arrived late and found some parents had left. Even then, a good number of parents were still waiting for us. The parent-led support group

viewed the low turnout not as a failure, but rather as a step towards another opportunity in the future. Parents assured the community that they would come again for another meeting. The meeting was a success despite it being short, lasting for only one hour. Participants asked some questions and were able to network with the support group after the meeting. Parents observed that they planned for a meeting with ASD parents only but had to quickly adjust to meet the needs of all participants who included parents of children without disabilities and those with other disabilities. Parents did not want to disappoint other parents of children with other disabilities but took the opportunity to teach the community about ASD. The flexibility of the parents worked well as they captured a larger audience to help disseminate ASD awareness messages in the community.

6.8.4 Reflections and learning: Now they know ASD

During the reflection meeting, parents realised the need to be flexible and quickly adapt to the needs of the community. The parents' discussion had to incorporate the needs of all the groups present. The message parents presented to the group was on cross-cutting issues about disabilities, which included loving children with disabilities and avoiding discriminating against them. Parents further realised that one way to reduce stigma and promote an intensive campaign for ASD was to involve children with ASD themselves to speak for themselves. As a support group, parents realised that most often children with ASD were left out during advocacy meetings. The presence of a child with ASD during meetings stimulated parents to pay more attention and understand what it meant to have a child with ASD.

When we went to Apollo, (Chilanga rural) a lot of people got the message and a child with autism suddenly appeared from nowhere in the room. It seems that it is God who sent him to the meeting so that everyone can see what we were talking about. (Parent: MM6 P1).

The presence of the child attracted the attention of many participants who included journalists, teachers from the mainstream and community leaders, who started asking more questions about ASD. This impressed much in the minds of the parent-led support group regarding the need to involve ASD children in awareness campaigns. Another lesson learned was the need for the community to understand that children with ASD were not mentally ill, as perceived by the

community. The community normally discriminate against them, resulting in children with ASD living isolated lives or having only specific people with whom to associate. The special education teacher who was so passionate about this research study warned the participants against mistreating children with ASD as they were normally considered as mad: *When he sees people he runs away, we need to love him.....* (MM5 TR1). This was a sign that there is social discrimination against children with ASD who are believed to be mentally ill. I thought that this cycle also showed the reality of advocacy and awareness in rural contexts – the logistics and the need for flexibility, which the parents demonstrated.

6.9 Action Cycle 5: We need to publish our stories and reach a wider community

In this action cycle, parents decided to publish their stories to capture a wider readership. Two articles were published, one in the public media in a state-owned institution and another in the private media run by individuals (Appendix O).

6.9.1 Plans: The world must know about ASD

Action Cycle 5 runs through other action cycles. This means that Action Cycle 5 is an action within other action cycles. Realising that the major barrier to ASD support services was a lack of adequate awareness of ASD in society, parents planned to publish their stories in newspapers and on social media to increase the number of people who would read about ASD. The aim was to make journalists and media houses organisations be aware of ASD. Parents decided to invite journalists from the print media to cover the events. This was also an opportunity for journalists to learn about ASD. The following activity were planned:

- Publish ASD awareness stories in print media (newspapers).

6.9.2 Action: The power of media houses as tools for social change

Members of the parent-led support group managed to publish two newspaper articles in both the public and private newspapers. The publication of the stories excited parents because ASD messages was reaching a wider readership. The first article talked about the need for parents and communities to understand the educational needs of children with ASD and that parents should not force their children into formal education. This article was published from the lessons learned during the workshop conducted on 23/09/2018 for both parents and professionals. The second publication (Diggers Newspaper) highlighted the need for more research in ASD and to have more NGOs advocating for ASD. The newspaper article was

published after parents had a meeting in Chilanga. Parents also joined other social media ASD platforms which had professionals in the groups. They also formed a parent-led support group specifically for this research. These platforms were used by parents to reach the wider community.

6.9.3 Observation: Our stories are impacting the wider community

We realised that each time a story was published in the newspaper, and it was re-circulated on other ASD online groups and to friends and relatives we would receive a lot of telephone calls and even verbal compliments from the community. Parents observed that the publication of the stories in the newspapers created an opportunity for networking with journalists and reaching a wider English reader audience. Journalists who attended the capacity building workshop in Lusaka and the ASD awareness meeting in Chilanga were made aware of ASD. One of the journalists said, *“I am hearing about ASD for the first time.”* As part of extending awareness-raising to journalists, he was also given the four ASD awareness rubber bands (Figure 6.4).

The only challenge observed was that many people who did not read English were denied an opportunity to read about ASD. Another challenge was that only few people can buy the newspapers because the cost of buying a newspaper is very expensive and hinders efforts to reach many more people in Zambia. The other barrier was that as much as we planned to publish our stories, newspaper circulation was mostly in towns and not in rural areas. The newspapers both public and private do not publish newspapers in local languages.

6.9.4 Reflections and learning: The emancipatory and advocacy journey begins now

The last reflective meeting was held on 5th October 2018 in the CDC conference room. The group agreed to discuss lessons learned during the Chilanga trip and general lessons learned during the whole research period. The first activity was to discuss the lessons they learned during the whole research study. Parents were initially shown some video clips of the fieldwork done during the research period. The last meeting was part of the general reflective learning that highlighted the lessons learned during Phase two. I appreciated their level of maturity and respect towards each other, the determination to support each other and the parents’ willingness to talk freely about their children’s condition to the public. This is a phenomenon which was not common among Zambian families of children with disabilities such as ASD, because of stigmatisation and discrimination.

6.9.4.1 Thinking through the empowerment process

During reflection and action learning at the Chilanga meeting, parents were happy that the knowledge and skills they had acquired during the workshop in Action Cycle 3 were put to good use by sharing them with other parents in rural areas. The use of local languages during the discussion made many participants understand the topic well, and the participants were free to contribute to the discussions.

The distribution of materials worked well to promote ASD awareness. We might have needed to think of having some materials like the rubber bands written in local languages to capture all the groups of people in rural communities. Even though the meeting was delayed, the parent-led support group would not give up on the trip. The participants had to wait for a long period of time. This showed the African culture of not wanting to disappoint the visitors and the willingness to wait and hear what the visitor plans to share with the host.

6.9.4.2 We are no longer disempowered

During this reflection meeting, parents said that they had learned much:

One thing I have learned is that am not alone. There are many parents with similar challenges. I have also learned that these children can be taught. They can learn all other things despite that they cannot express themselves fluently. (Parent: MM2 P2).

As a parent of a child with ASD, I have learned that we need each other not necessary for consolation but knowledge. We need to share knowledge and we should not leave as islands but embrace each other. (Parent: MM2 P5).

I learned that we need to love these children and care for them. One day they may leave an independent life. (Parent: MM2 P7).

Parents were empowered and the onus was on them to continue acting on issues affecting them:

The biggest lesson, I have learned is that the onus is on us to advocate for these children. At times we get discouraged by people's negative

comments because they are ignorant about ASD. We have the privilege to learn as we have done. (Parent: MM2 P3).

Participants were ready to sustain the project: *This should not be the end, but the beginning of the future for our children* (Parent: MM2 P6). One way to sustain the advocacy activism was to join existing ASD organisations: *I think, we can work with organisations like Mulenga Autism Foundation* (Parent: MM2 P6). A year later, in 2019, I learned that parents in partnership with Mulenga Autism Foundation had continued to meet. They visited Chipata Township for ASD awareness meetings and went back to Chilanga for similar ASD meetings.

The major lesson learned during the Chilanga trip was that many people did not know about ASD but were ready to learn. Terminating the research project was an emotional and challenging decision for me to make. I assured the parents of our continued networking, even after my thesis was completed.

6.10 Summary of the chapter

Parents learnt many lessons as they actively participated in finding solutions to challenges affecting them. Throughout the action cycles, parents were able to empower themselves and to provide the community with much-needed knowledge about aspects of ASD. This was achieved largely through a reflective action learning process. The chapter has shown that parent-led support groups can bring about social change in the community. It has demonstrated how the PAR approach benefitted both the researcher and the subjects.

CHAPTER SEVEN

THESIS BUILDING: DISCUSSION AND INTERPRETATION OF THE FINDINGS



Figure 7.1: Parents likened to noble eagles (Picture by Katisha Siabong’a Nyoni)

The above figure shows an image of how ASD parents can be likened to noble eagles that aim to meet the unmet needs of the eaglets regardless of the barriers they may face.

Teams of people working together for a common cause touch all our lives. From everyday activities like air travel, firefighting, and running the United Way drive, to amazing feats of human accomplishment like climbing Mt. Everest and reaching for the stars, teams are at the centre of how work gets done in modern life (Kozlowski & Ilgen, 2006, p. 78).

7.0 Overview of the chapter

A family is a critical unit in the social-emotional well-being of a child. The United Nations Convention on the Rights of Persons with Disabilities, (UNCRPD) emphasised the need to protect the rights of families of children with disabilities. It states that: “family members should receive the necessary protection and assistance to enable them to contribute towards the full and equal enjoyment of the rights of persons with disabilities” (United Nations Convention on the Rights of Persons with Disabilities, 2006, p. x).

Zambian parents of children with ASD are no exception to enjoying the rights as stated by UNCRPD. However, it was observed that parents of children with ASD in Zambia have many barriers in accessing the services. The quote at the beginning of this chapter by Kozlowski and Ilgen (2006) illustrates how parents in this current study worked as a team to address some of the barriers they experienced in accessing services.

In the two previous chapters, I discussed the findings of the study. In this chapter, I delve into the meaning, importance, and relevance of my findings in relation to related literature. I base this discussion on five action cycles of the empowerment of parents through a qualitative PAR approach. The five actions taken by parents are:

- Parents creating a common identity with one love and one heart: Drawing on traditional support.
- Upsetting the apple cart – reconfiguring relationships with community and service providers.
- Building bridges of partnership between parents and professionals.
- Lift as you raise.
- Back to the roots: Creating ASD awareness into the broader community.

Figure 7.2 below shows the five action circles depicting how the process of parents’ empowerment happened among parents themselves and in the community. The two arrows in the figure show how each level of action the parents took increased their empowerment abilities.

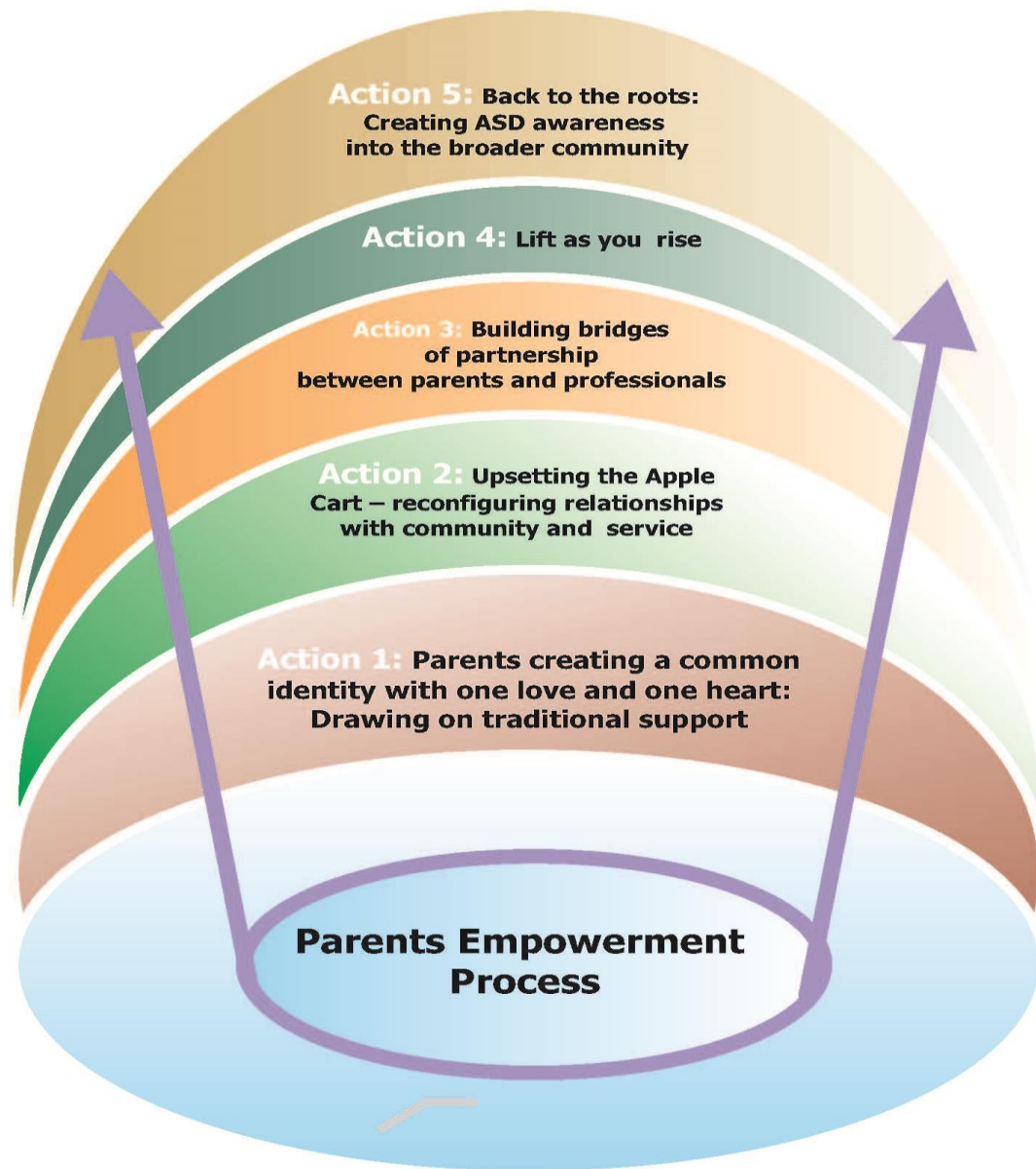


Figure 7-2: Parents' empowerment process

7.1. Action 1: Parents creating a common identity with one love and one heart: Drawing on traditional support

To develop a common identity with one love and one heart, parents created a parent-led support group. The support group was used by parents to share their unmet needs such as barriers in accessing quality health services and what it means to be a parent of a child with ASD. In addition, belonging to a support group gave the parents a sense of identity and an avenue to collectively address their concerns. Through sharing their lived experiences, participants were able to transform and improve the society they live in (Mertens, 2003), emancipate themselves and fight social injustices created by the community (Kincheloe & McLaren, 2005).

In this study, parents reported that caring for a child with ASD is stressful, which is consistent with previous study (Shepherd, Landon, Taylor et al., 2018). The implication is that parents were likely to experience mental distress if their needs were not addressed. This is because having a child with ASD requires special attention and families must adopt unique ways of parenting styles. This includes parents learning different ways to interact with the child and how to navigate the relationship with their children (Algood et al., 2011). Parents sometimes had to adjust in their relationships with the child with ASD, for example changing their habits of when they eat and sleep. These concessions may lead to better caregiving, hence reducing the parents' stress. However, irrespective of the adjustments they make, some parents may still require formal support services because of the increased stress that comes with caring for the child with ASD (Banach, Iudice & Couse, 2010). Access to formal support services assists families to meet their support-related needs (Harper, Dyches, Harper, Roper, & South, 2013; Smith & Anderson, 2013) to enable them to live a quality life and manage the behaviour of their child.

A study conducted in Iran by Samadi, McConkey, and Kelly (2012) among parents of children with ASD revealed evidence of reduced stress and improved family functioning among parents that access support services. In my study, there was a perceived reduction in stress levels among parents who joined the support group. The parents who had been surly at the beginning showed significant engagement with each other after some time being in the support group. The level of engagement in the support groups increased as they shared their lived stories and took part in reflective learning activities. It seemed that the support group in the current study acted as a

buffer to parents' social-emotional challenges, and acceptance of the child's condition, hence reduction in stress. A literature search provides adequate evidence that parents who belonged to support groups demonstrated lower depression (Benson, Daley, Karlof, & Robison, 2011; Wei et al., 2012), and developed coping mechanisms for their emotional, social, practical, and informational needs (Tehee, Hevey, Tehee, Honan, & Hevey, 2008; Stahmer et al., 2016).

Parent-led support group creates opportunities for both the parents and professions to share and identify available services in the community regarding a child's health condition (Pandey & colleagues, 2021). Mia (2009) conducted a study among Israeli families of children with ASD who formed a support group and shared advice on how to support a child with ASD during the Bar Mitzvah rite of passage, a traditional rite of initiating a child into Jewish adulthood. The findings revealed that the advice from the parents in the support group assisted other parents to initiate their children into the Bar Mitzvah rite of passage. The findings are consistent with those of the current study where parents indicated that joining a parent support group was empowering as it enabled them to get emotional and financial support and identify other ways of addressing common challenges. Seeing others contending with the same unmet needs and making progress in their lives was inspiring and encouraging to parents. This contributed to the parents accepting their child's condition. Some even offered to volunteer to advocate for the rights of their children in the community.

To consolidate the collectivist African way of supporting one another, parents had to first choose leaders to coordinate activities. These leaders were chosen based not only on their education and schooling experiences but also on cognitive clarity and social responsibility. This contrasts with a study by Jackson et al. (2018) who urge participants to elect leaders based on their education. In local communities, the choosing of community-based leaders among the peer support groupings should not be based mostly on school-based intelligence, but on the following characteristics as observed by Serpell and Jere-Folotiya:

Nzelu encompasses the English notions of intelligence, wisdom, cognitive alacrity (*cenjela*), and social responsibility (*-tumikila*). To qualify as *-nzelu* within the system of meanings that informs the indigenous culture of Chewa village life, an individual must display both cognitive alacrity and social responsibility (Serpell & Jere-Folotiya, 2008, p. 4).

In Zambian traditional settings, Robert Serpell and Jere-Folotiya (2008) additionally argue that leaders are not chosen based on formal Western standards of intelligence, like academic qualifications, but on capabilities. This is because local people have contextual intelligence about their community which is beyond academic knowledge and cannot be ignored. All members of the community are considered to have something that they can contribute to the community. Proverbs like *Chala chimodzi sichitola nsambwe* (One figure does not pick lice) illustrates the benefits of teamwork; how each community member is valued and respected. It was observed in this study that all members had a role to play in bringing social change to the group and the community. This is because parents realised that they had many things in common regarding barriers to ASD services, an aspect that bound them together.

Despite some members in this study not being educated and having informal employment, they exhibited capabilities of contributing to ASD advocacy. This is in line with the capability framework as alluded to by Sen, (1979) who observed that each person is capable of contributing something to the group or community.

The capability framework describes the knowledge, skills and abilities needed to perform work. Sen, (1979) further urges individuals to practice their freedom to choose leaders and to function according to their potential. This freedom should bring hope to the community (Coleridge, 1993). Studies have shown that individuals with capabilities have the freedom to choose what is right for themselves (Sen 1979,1985 and 1993). Parents in the current study showed their capabilities by not only creating a support group but also by selecting their leaders, identifying their unmet needs as well as deciding on the type of action, time to meet and where and when to meet. Such freedom and capabilities became more beneficial with the support of a Critical-emancipatory theoretical framework, which was employed in the current study.

The use of a Critical-emancipatory framework exposed “the forces that prevent individuals and groups from shaping the (ir) decisions” (Kincheloe & McLaren, 2005, p. 308). Parents emancipated themselves during action reflective learning meetings and took the initiative of dialoguing with various professionals and community members. Such capabilities exhibited by the parents showed how each parent has the potential to advocate in future for change in their respective communities.

Studies have shown that the capabilities of local community members are seldom respected by academics despite the potential members have to empower themselves and bring social change in their respective communities (Hope & Timmel, 1986; Kramer-roy, 2015; Lorenzo, 2005). Oftentimes, the voice of the poor may not have the same capacity and power to make decisions that can bring change in society as compared to the rich (Taylor, 2000). The World Health Organisation urges its member states to respect community-based knowledge as it gives a voice to the local community and defines their destiny (World Health Organisation, 2010). Therefore, researchers and project initiators and implementers should not force their knowledge, ideologies, and culture on local people to foster community development or social change. It was revealed in this study that all 17 parents showed the capabilities to make personal and independent decisions to actively participate in different activities that aimed at improving quality of life. This was shown when they could volunteer to attend meetings, plan, and implement the planned activities. This is consistent with the Human Scale Development (HSD) framework where an individual's quality of life is determined by the opportunities they may have (Van Zyl, 1994). Human Scale Development focuses on the satisfaction of fundamental human needs. It is based on promoting self-reliance, and participatory democracy. The model also foregrounds the process by which communities can identify their "wealth" and "poverties" according to how these needs are satisfied. These participants in this study were able to apply the Human Scale Development model by showing their resilience and self-determination by advocating for the rights of their children. The advocates' activities were conducted in places like churches and hospitals where they had been previously denied the right to access quality services. These participants in the current study had to take the economic and emotional risk of working together for ten months to raise ASD awareness. It appears parents were motivated as a group to bring social change to their community. This is because they had a common agenda and faced similar challenges. Literature attests that people with a common agenda may be intrinsically motivated to advocate for social change in their community as a group (Metz, 2011). Such groups of individuals are capable of sacrificing their resources and time to fight for social justice in their respective environments (Shultz et al., 1995). It is evident that the people become advocates for political change in the community and they do this with the support of other empowered people and, collectively, promote political change in their community (Carr, 2003).

The agenda of focusing on social change at the community level is supported by the Human Scale Development (HSD) framework which advocates for people-centred development practices. The people-centred framework gives the affected group a voice to express their voices and own the activities (Baum, et al., 2006). The HSD framework further states that human development should be centred at a local level of the human scale or local community, rather than at national or international levels (Van Zyl, 1994). This is in line with the Bio-ecological theoretical framework used in this study that promotes interconnection between the affected group and the local environment.

For human development to be achieved at a local community level, it is important to have a support group that has flexible structures (Jackson et al., 2018). This is because having flexible structures and content in support groups can assist to empower participants to freely share ideas, dialogue, plan and implement their activities (Mahmoudi, 2014). On the other hand, rigid structures and content can disempower individuals. In such instances, there is a danger of having disempowered parents taking up a leading advocacy role of social change in their community. Such disempowered individuals might at times inadvertently mislead the community because of limited knowledge about the content of the phenomenon (Sue & Sue, 2003).

Therefore, support groups should aim at having flexible structures and content (type of activities parents engage in) mostly in communities where the majority are illiterate. Support groups should be avenues of accessing non-professional, non-material, and non-coercing support from a group member (World Health Organisation, 2019). In the current study, parents benefited from material and non-material, financial, non-professional support. This was achieved during action reflective meetings where they at times worked in pair works and conducted brainstorming sessions (see chapter six).

Parents equally shared stories of fear, anxiety, stress, community stigma and hope. Literature shows that social stigma and discrimination have continued to disempower parents globally (World Health Organisation (WHO), 2011). This has caused parents of children with disabilities to live isolated lives as discussed in this study. Many parents narrated living isolated lives, had to stop attending social events. It was sad to learn that even their children with ASD complained of social and emotional abuse by peers. Stigma and social isolation can reduce when the

community, policymakers, and professionals are made aware of ASD. National policy documents that deal with disability rights such as the Zambia Disability Act should be implemented using the affirmative action approach where stringent measures are put in place to punish individuals and organisations that do not adhere to policy directives.

The continued stigmatisation of parents and families of children with ASD has a negative implication on parents' health. Social stigma creates stereotypical behaviours towards affected individuals because perpetrators discredit affected groups, resulting in such groups being denied access to goods and services (Kinnear et al., 2016). Parents in the current study used their strength in numbers to advocate against discrimination and social stigma. These parents had to dialogue with perpetrators of stigma and discrimination in communities and even among professionals both in the education and health sectors. This has highlighted the power in numbers and teamwork. Having large numbers of participants with one agenda promotes teamwork whose influence can be used to bring social change in the community. The support group with a significant number of members can deal with “structures and processes which create disability, and (lead to) the establishment of a workable dialogue between the research community and disabled people” (Barnes, 1992, p. 122), fellow parents, local community members and professionals. In addition, a support group motivates participants to develop a sense of acceptance (Mandell & Salzer, 2010).

Similar findings were observed in this study where parents developed a sense of acceptance of the ASD condition through sharing their experiences with the community and accessing informal counselling. Informal counselling was also provided from a tribal-cousin perspective called ***Chibuya (cousin)*** practised among different tribes in Zambia (Zimba, 2014). Tribal cousinship is a social ‘passing time’ activity that is displayed at various gatherings such as marriages, funerals, and other social occasions. The traditional cousinship ‘***Chibuya***’ (cousins) date back to the 19th century and it has been used in Zambia to maintain peace and co-existence among the 73 tribes found in Zambia (Zimba, 2014). For example, if one tribal cousin has a funeral, the other tribe takes up the responsibility of funeral costs and other activities such as cooking, counselling the bereaved, digging the grave and sleeping over at the funeral house until the day after the burial. As part of lightening the burden, the bereaved tribe may be smeared with a white pounder, forcing them to contribute money or materials such as shoes, mealie

meals for the funeral expenses. The money and any other materials collected during the funeral are donated to the family of the bereaved. This money is meant to cushion the bereaved family and assist them to sustain themselves and meet other funeral expenses that may have occurred during the funeral, thus lightening the burden of mourning and funeral expenses. I observed that informal traditional group counselling is part of the Zambian culture and it worked well during the parent-led support group. The Chibuya-traditional counselling in this study was most practised among Bemba parents against Ngonis and Tongas with Lozis. This type of group counselling and support is provided free.

There is a need to explore how cultural community counselling under Chibuya-traditional relationships can be promoted to support parents of children with ASD in societies where there is limited investment in mental health (Davids et al., 2019; Kapungwe et al., 2010; Ngungu & Beezhold, 2009). Kapambwe and colleagues (2013) used the existing cultural structure in the community *alangizi* (traditional marriage counsellors) to provide counselling services to promote cancer awareness (Kapambwe et al., 2013). Alangizi provides counselling to girls who enter puberty. The topics that alangizi teaches the girl child varies. Kapambwe and others (2013) further observed that some of the topics which Alangizi teaches are about child respite care services that the parents need to access or provide to others in the community. The same approach can be replicated to promote ASD awareness in the community.

Respite care is the support used by carers to “mitigate the stress related to the demands of caring by allowing time for them to rest and do things for themselves...” (Neville et al., 2015, p. 51). The utilisation of formal respite care appears to be low in many lower and middle-income countries (Neville et al., 2015). It was observed in this study that parents of children with ASD indicated experiencing challenges in accessing quality formal respite care support in their communities from professionals. Accessing respite care support gives parents to refresh and live a normal life away from the child's daily burdens (Murphy & Verden, 2013; Neville et al., 2015). The current study revealed that many participants were sole carers. Single, working mothers, great grandparents and widowers were the most affected group. This resulted in frequent hiring and changing of caregivers who could verbally and physically abuse the child as part of disciplining the child. For example, it is noted in this study that parents could find

their children abused by hired caregivers who could not understand the child's behavioural challenges. This forced the parents to frequently change the hired caregivers.

However, the experiences of parents as sole carers may appear to be a strange phenomenon because the Zambian community practices a collective community family system (Awopegba et al., 2013; Mbiti, 1969; Nsamenang, 2006). The proximal and reciprocity culture extends to how the community can support the care of a child in the local environment. In such societies, the burden of raising a child is not the sole responsibility of one parent, but a collective duty of the whole community (Mbiti, 1969; Nsamenang, 2006; Snelson, 1974). The child belongs to the community (Mbiti, 1969) not to parents alone. Therefore, the pain of one parent is the pain of the whole family (Kang-Yi et al., 2018). Terms like '**bo-popular**', meaning 'God's creation' is used by the Basotho people of Lesotho showing that we are all equal (Sefotho, 2021) and we all need support from one another.

However, despite considering that all people are equal in the sight of God, parents in this study narrated how they could not get the support that they expected from their respective communities including the church. This is because many African traditional structures have been eroded by Western education and its cultures on living an individualist type of life. This is against the cultural norms in among the Zambians. According to Zambian cultural norms, providing short- and long-term support to community members is part of cultural obligation whereby the responsibility of caregiving is considered as a reciprocal responsibility, with caregivers providing the support now to a child with the view that in future the child may do the same to them. A ChiBemba proverb states that *Mayo impapa naine inkakupapa* (Take care of me today, tomorrow I will do the same). Traditional leaders, older parents, Non-Governmental Organisations, religious organisations, political leaders and the government need to educate the society on the need to practice *ubunthu* and bring awareness to the community about disabilities such as ASD.

Murphy and Verden (2013) also suggest the use of undergraduate students as respite carers to support families of children with ASD. Undergraduate students as aided caregivers provided opportunities for prevocational training and experience as well as increased opportunities for parents'/guardians' engagement in other activities without involving their children. The

methodology used by Murphy and Verden (2013) might be appropriate to nations like Zambia as it is a cost-effective way of providing support to families of children with ASD.

Creating a common identity was observed when parents created their online support group and introduced some parents to some existing ASD online support groups. Parents used the platforms to share their daily challenges, communicate planned activities and evaluate the implemented ones. They shared their thoughts, feelings and burdens at any time and could get quick feedback from fellow parents. Forming an online support group increased parents' sources of accessing information and sharing their emotional needs at any time without any personal contact. In addition, it provided less restricted space for advocacy as compared to face-to-face groupings. Parents could post their feelings, thoughts almost at the same time or at their own convenient time. This finding is consistent with other studies (Alsem et al., 2017; Anthony et al., 2020; Zhao et al., 2019) where online support groups increased parents' access to more information and communicate with others according to their schedules (Mulenga & Marbán, 2020).

This section has shown the value and benefits of forming a parent-led support group. It has shown how parents had one agenda that needed to be achieved. In addition, the section has highlighted how parents came to appreciate that the agenda can be achieved by, first, sharing common stories and, secondly, acknowledging that their stories and experiences were similar, hence working as a team.

I now discuss how parents used the power of a support group to 'upset the apple cart' and reconfigure their relationship with the community and formal service providers where parents became ASD experts.

7.2 Action 2: Upsetting the apple cart – reconfiguring relationships with community and formal services providers

Donating your time to advocate for social change to those around you is extremely important to both the parents and the community. Parents in the current study were able to lift the lives of others in their respective communities. This is because parents were aware of how burdensome and stressful it is to have a child with ASD (World Health Organisation, 2013b). To mitigate the challenges, professionals and the community were

required to offer support to affected parents on how to adapt to the diagnosis, manage the behaviour of the child and access early intervention services (Abubakar, Sewanyana, De Vries et al., 2016).

It was observed in the current study that, despite professionals being held in high esteem by parents, they had limited knowledge about ASD, its scientific causes and management. This forced the parents to seek alternative sources for knowledge of ASD, for instance from the traditional healers. Stekelenburg et al. (2005) observed similar findings in a study conducted in the western part of Zambia where many parents accessed traditional healers' services as compared to medical health. This was because accessing traditional medicine and other cultural related services is part of the Zambian culture that has been passed on from one generation to the other. Studies have shown that about 80 per cent of the Zambian population uses traditional and alternative health services for their day-to-day health care (The Government of the Republic of Zambia, 2012b). Similarly, Ndubani and Hojer (1999) conducted a qualitative study on the role of traditional healers in Chiawa, a rural part of Southern Zambia. The findings further revealed that the community believed that traditional healing was part of their life. However, despite some parents accessing traditional healers' services, this study revealed that even traditional healers were perceived as a novice to ASD diagnosis, treatment and how parents could care for their child with ASD. This led some parents to seek church services.

The church is an expert in curing different types of diseases. In addition, the church is considered as a place of solace for those facing challenges in life. It also plays a critical role in the lives of parents of children with disabilities (Weisner et al., 1991). The church has clergies who are perceived to possess divine power to cure disabilities (Mwale & Chita, 2016) and intercede between the people and God (Stekelenburg et al., 2005). Both the clergies and the church community members provide support to fellow church members. It was not surprising in the current study that parents had to seek the cause, diagnosis, and treatment of ASD from the church. This is because statistics show that over 90 per cent of the Zambia population are Christians (The Government of Republic of Zambia, 2012a) and Zambia is constitutionally recognised as a Christian nation (The Government of Republic of Zambia, 1996b).

However, despite parents seeking help from the church, it was evident in the current situation that religious leaders had limited knowledge and understanding of ASD. The parents were

further disempowered by this, and they could not find solace in the church. Parents, mostly mothers, reported being side-lined and discriminated against by both religious leaders and church members who did not understand ASD. Many church members who may consider themselves as religious experts in casting out demons and providing healing services are not aware of what causes ASD. These leaders who are a novice to ASD may not know that some children with ASD experience higher levels of sensory challenges that makes them sensitive to loud sounds, lighting systems, being confined to one place and being in large crowds (American Psychiatric Association, 2013). The reaction of the children to such stimulants can be misunderstood as misbehaviour, which is against the conduct of the church. Considering that the church lacks ASD experts, Luther et al., (2005) observed that many parents hardly participate in religious rites because of the child's behaviour. Consistent with the current study where parents could stop attending religious services because of the child's behaviour and negative attitude from the church. Some parents reported having 'fights' with religious leaders who denied children the rights to religious rites such as baptism. Sideling and discrimination of parents by the church resulted in lamentations by parents who starts questioning God why they had to have such a child and why should it be them.

However, resilient parents narrated to fellow parents in the current study how they managed to navigate their way into church activities for the sake of their children. These parents were able to show their skills as ASD experts by becoming teachers of their own children instead of stopping going to church. Richie (2015) advocates for religious leaders to develop curriculums that promote the theology of disabilities. Religious institutions such as seminaries and universities that train clergies need to incorporate content in their curriculum on disability studies which includes ASD. Studies show that receiving spiritual support can help parents cope with the condition (Richie, 2015). In the current study, however, the services provided by the church were not satisfactory and increased parents' stress levels as they searched for cures and treatment from health professionals.

Professionals in the formal sector such as clinicians were also considered as novices. Parents reported enduring bureaucracy to access services from clinicians who they held in higher esteem as ASD health experts. One of the barriers to parents' unmet needs was the tedious health referral system used for a parent to access medical consultants on the health matters.

According to the Ministry of Health referral structure system, the first referral point is the health community and then the health posts. This is followed by health centres, 1st level hospital (district), 2nd level hospital (general) and 3rd level hospital (central) (The Government of the Republic of Zambia, 2012). It is at the 3rd level hospital that parents reported accessing the services of skilled ASD professionals. These clinicians were found at only the University Teaching Hospital and Developmental Intervention Clinics the whole Zambia. This meant that all parents who even suspected that their child had ASD were referred to UTH in Lusaka district. Some parents had to cover over 3000km to and from their districts using public transport whilst travelling with a hyperactive child. This discouraged parents to continue with therapy services.

In all the referral health settings, parents had to go through long queues, long hours of waiting and long appointments multiple times. It could take between six to 12 hours before being seen by a specialised doctor whilst confined in one place with the child. In addition, there was little regards to previous reports and documents by each professional at each referral level. Each referral level had to start afresh with investigations which could take longer. This is mirrored in a previous study where parents complained of long appointment dates that in some cases took over six months before parents could see a specialised doctor (Nyoni & Serpell, 2012). Clinicians may not be aware of the burden and how stressful it is for parents to keep a child with ASD in one place for a long time in long queues. In additional, clinicians may take it for granted that all parents are from Lusaka and may not understand what it means to travel with a child with public transport when going to the hospital. Professionals may not be aware that the lack sensitivity to parents' concern contributes in delaying to access the services. Literature shows that parents who delay accessing early diagnosis services experience greater burdens with a high likelihood of the child being dependent on the parents even in adult life (Müller & Cannon, 2014).

To upset the apple cart, parents had to actively participate and play a leading role in bringing social change among the professionals. This is supported by the Critical-emancipatory theoretical framework which urges affected groups to actively participate in finding a solution to barriers affecting them (Cornwall & Jewkes, 1995). Parents became experts of ASD whilst professionals were considered novices. The Sesotho proverb of **Sehole ho 'Ma-sona ha se lahlloe'** [A child with a disability is never abandoned by the mother] in Lesotho urges parents

to play a leading role in advocating for the rights of children with disabilities if the community was to accept the child (Sefotho, 2021). The parents in the current study showed a sense of self-confidence by taking awareness messages to professionals in their respective institutions. A study conducted in the United Kingdom reveals similar findings where parents as experts were able to provide highly technical and intensive care to a child with severe health conditions that "would previously have been considered to be the domain of professionals" (Kirk & Glendinning, 2002, p. 625).

Parents had to fight against all odds to claim their position of being ASD experts. This included being resilient, rejecting bureaucratic structural systems in accessing services (Nyoni & Serpell, 2012). A classic example of a bureaucratic structural system is the Ministry of Health, where one must pass through many levels before reaching level 3 hospitals, which offers comprehensive services (The Government of the Republic of Zambia, 2012b). This type of quality service provision and management gives absolute power to managers and professional (Mpolomoka et al., 2019) and disempowers local people. The result is a society where laws established do not take into consideration the challenges affecting the parents. The literature revealed that professionals that work with parents in community-based programmes are likely to benefit from parents' rich knowledge and their lived experiences about ASD (Kirk & Glendinning, 2002).

In this study, parents engaged professionals in social dialogue by highlighting the different topics on ASD which include the cause of autism, its diagnosis, treatment, challenges, and the burdens of accessing the services. The opportunity of dialoguing with professionals created another avenue for the flow of information from both up-bottom and bottom-up engagement (Mpolomoka et al., 2019). The bottom-up approach used by parents has some benefits. It gives power to grassroots people (WHO, 2010), and local people are respected as experts, capable of contributing to social change in their respective communities (Friere, 1970; Mahmoudi, 2014).

This is also mirrored in studies conducted in Zimbabwe (Hope & Timmel, 1986) and South Africa (Lorenzo, 2005) where local knowledge was considered important in empowering affected individuals. The use of local knowledge indirectly enables researchers to translate their scientific evidence into practical terms (Yusuf & Elsabbagh, 2015) and improves professionals' participation in local activities (Harper, Dyches, Harper, Roper, & South, 2013). This is

consistent with the current study where professionals demonstrated an appreciation of parents' local knowledge about ASD and what it meant to be a parent of a child with ASD. To consolidate their empowerment process, parents had sought to build bridges of partnership with professionals by negotiating the power imbalances that exists when accessing formal services from the professionals. Parents in the study increased their involvement in the welfare of their children in finding solution to challenges affecting them. Nachshen, (1997) equally observed that empowered parents were involved in finding solution to challenges affecting their children. The section has shown how parents upset the apples. Parents continued with their awareness messages by building bridges of partnership with professionals as discussed below.

7.3 Action 3: Building bridges of the partnership between parents and professionals

This section describes how parents managed to build a partnership with professionals. This achievement was through a negotiation process. The first step that parents did was to identify their unmet needs, then later plan and conduct a one-day workshop. In this one-day participatory workshop parents and professionals had to brainstorm, debate, work in pairs and groups and conduct plenary sessions. The aim was for both groups to have the same understanding of the child's developmental milestones and how to access quality services. A workshop was important to parents. This is because most professionals in Zambia are perceived to still provide services using the traditional medical model of the disability to understand the cause of a disability. The medical model of disability is used to attempt to correct the disability condition (Oliver,1990). These professionals work within their area of specialisation by identifying the problem, diagnosing it, evaluating it, and making recommendations for further referral with little involvement of the parents. In such instances, parents are considered to play the traditional role of passive recipients of services (Friere, 1970). To claim their voices back, parents felt the use of a workshop would provide an opportunity to bridge the gap between them and professionals. The use of a workshop provided an opportunity for parents to freely express their views and create an opportunity to be viewed by professionals as also having expert knowledge relating to their child with ASD.

To build bridges of partnership and increase their own ability to work with professionals, parents in this study embraced a capacity-building approach and focused on providing interdisciplinary input during the workshop. The interdisciplinary approach looked at how to manage the behaviour of the child, home schooling and use of local traditional games, plays and materials to enhance communication and behaviour modifications.

The short participatory workshop which ran for a day seems to have had a lot of benefits to both parents and professionals. In this study, parents reported benefiting from engaging skilled professionals on different unmet needs that required them to have more knowledge and skills from a medical perspective. Some of the benefits included how to provide individualised education both at home and school with the support of teachers. Other benefits were appreciating of using local materials, traditional games, and stories to enhance language and social development in a child with ASD. The use of locally available materials is cost effective and stimulates a child to play with known available materials in their environment. It was also observed in this study that both parents and professionals had to develop a mutual respect and appreciated the rich knowledge that both groups had about ASD.

Literature has revealed that short workshops create a valued partnership between participants and professionals and it improves parents' identity, behaviour change, self-determinism, team building and competency (Samadi, McConkey, & Kelly, 2013). In addition, participatory workshops are important in capacity building individuals because they combine both formal learning (Kyndt & Baert, 2013) and informal learning models in imparting knowledge and skills to participants (Rüber & Bol, 2017). Studies have shown that participants are likely to invest in workshop programmes when they see that the activities planned contribute to the benefits of having more knowledge about ASD (de Grip & Pleijers, 2019). A good example is a study by Samadi, McConkey, & Kelly (2013) in which they observed that short workshop sessions of advocacy training make parents experience less stress. Stress can reduce if parents are educated on how to manage the behaviour of the child.

Globally, children with disabilities are the most marginalised and excluded groups who experience a wide range of violations of their rights (UNICEF, 2013), which include rights to education. These children may not only face challenges in their communities but also from the teachers (see chapter five). Educating a child with ASD is critical as it is one of the steps to parents' acceptance of ASD condition and it is also part of the therapeutic process (Dawson-Squibb et al., 2020). These children with disabilities require access to a quality education because of the many challenges they face, such as distance to school, poor parents' attitudes and negative attitudes by the community regarding disabilities (Malungo et al., 2018; United Nations Children's Fund (UNICEF), 2013).

Teacher attitude to their welfare is another challenge. The teachers, learners and the community discriminate against these children not only because of the nature of disability they may have, but also because of lack of understanding and knowledge on its causes and implications. In addition some community members have fear of difference, fear of contagion, contamination, negative religious or cultural views of disability" (UNICEF, 2013). This is further worsened by a hostile school and home environment that judges and labels both the child and parent by the condition the child may have, rather than by the potential that a child must excel even at school. This inequality contributes to children with ASD facing challenges in accessing quality education, hence denying such children their human dignity and the right to education (United Nations Children's Fund (UNICEF), 2006).

Parents in the current study reported having limited collaboration with teachers on how best to support the education of a child both at home and school. Many mainstream and special education teachers had limited knowledge about ASD and how to teach children with ASD. This barrier of parent-teacher collaboration was compounded by many factors such as teachers' negative attitudes towards teaching children with disabilities (Serpell & Jere-Folotiya, 2011). In Zambia, there are few teachers who have an interest in teaching children with ASD (Macha et al., 2020). Teachers teach ASD children out of passion and not because it is a policy issue that allows all children access to education regardless of their colour and disability (The Government of the Republic of Zambia., 1996a).

Equally, the current study revealed that most teachers had limited knowledge and understanding on how to support the education of the child with ASD both at home and school. I observed teachers shunned teaching special education because they are laughed at and demeaned by fellow teachers who label them as (*ba special*) (special teachers), meaning that disability is contagious and even teachers will become like their learners they teach. Equally, in this study parents felt it is the duty of a teacher alone to educate a child because they are trained and paid to do that. The lack of collaboration between teachers and parents revealed why some parents complained in this current study that their children were still in the same grade and learning the same things as compared to peers.

Most parents in the current study reported that they did not see the value of children to still be schooling despite seeing little progress in the academic of their child. However, despite this concern parents were still supporting and investing their children's education. This is in contrast with the study by Malungo et al. (2018) who observed that many parents of children with disabilities do not invest in the education of children with disabilities. This is further supported by Mulenga (2019) who said that some parents had a negative attitude to investing in the education of children with disabilities. The parents in the current study might have invested in the education of their children because they were younger, and most ASD children are intelligent but may lack communication and social skills which they might have thought would be overcome.

Therefore, parent-teacher collaboration is critical, mostly among parents of children with a disability because a school is seen as the most available therapy service to children. Dawson-Squibb and colleagues (2020) observed that in many lower and middle-income nations education is the only available early intervention service for children with disabilities. The story is similar in Zambia where parents in this study were able to access education for their children even in rural areas. This provided therapy to the children with ASD, although many teachers did not have much knowledge on how best to educate ASD children and provide early intervention services.

Therefore, parent educational involvement and parent-teacher relationships are cardinal in supporting the child's education outcomes because it has some implications for families of children with ASD (Garbacz et al., 2016). The education outcomes may include the child developing survival skills, increasing social interaction both at home and school. The child can also appreciate the school and home environment as a haven of safety and security. For example, Korean families of children with ASD collaborated with teachers in negotiating power on how best to support children with ASD (Blair et al., 2011). The foregoing study showed that children's behaviours improved and there was an increase in teachers and parents' positive interactions with the children.

As the benefits of the parent-teacher partnership increases, parents-professionals' interaction also improves the support given to a child (Blair et al., 2011). Parents-professional collaboration promotes home schooling as well, and the child's communication and appreciation of the parent's experiences (Geiger, Smith, and Creaghead (2002). Furthermore, it improves the behaviour of the child with autism (Blair et al., 2011; Macha et al., 2020) and increases the networking system between the two groups.

In the current study, parents-professional collaboration promoted transparency on how to deal with challenges affecting the parents and even professionals when providing the services to parents. This is consistent with the study that has shown that the parents-professionals relationship promotes transparency when dealing with issues affecting parents (Mereoiu et al., 2016; Ruble & Dalrymple, 2002). The findings in the literature above support the current findings in which parents and professionals were able to engage in different activities relating to the child's developmental milestones from both the African traditional perspective and the contemporary medical viewpoint.

The parents-professionals' collaboration increases the trust between both groups and assists parents to develop ways of engaging with the struggles they experience when accessing educational services. It also helps parents navigate a system that is perceived as rigid, cumbersome, and stressful when accessing the services. This is because parents normally find themselves in the position of having to plead with the professionals to get the support they require (Cameron, 2018). These dilemmas contribute to delays in accessing early education intervention services.

Promoting parents-professional collaborations contributes to the increase in equity, efficiency, and access to quality evidence-based education. Investing in such a model can empower both teachers and professionals in the provision of quality education. Such an approach also favours the empowerment of families of children with ASD. This is because there is an assumption that the influence that professionals have on parents increases decision-making in parents and improves with a child's early intervention (Dempsey & Duns, 2004).

To improve parents-professionals' collaboration, parents used forms of practical help, namely active participatory, dialogue and decision-making and goal-setting . The four were used as tools of empowerment to parents.

Active participatory approach: During the workshop participants actively participated in making decisions about their welfare and that of a child. This strategy assists parents to have their voice heard and practical skills appreciated. The skills exhibited by parents also empowered parents to appreciate local knowledge.

Dialogue: Parents were able to dialogue with professionals about how they feel side-lined by professionals on the understanding of developmental milestones of a child from an African traditional education perspective.

Decision-making: Parents felt that some decision has to be made regarding accepting their local knowledge about childcare and treatment. For example, some of the practices which formal professionals such as clinicians call myth were not a myth but have similar health messages like those from the Global North medical scientists. It was the view of parents that African traditional education knowledge on health matters need to be incorporated into the medical and school curriculum. The knowledge gained would empower professionals to be sensitive towards the culture of the local people.

The three forms of practical help reduced the gap between parents and professionals and empowered both to appreciate the independent role which both play in child development. This was another higher cognitive thinking level that parents introduced to professionals of collaboration with a purpose and a goal to achieve.

Goal setting: Parents had to set goals of negotiating the power imbalances that exists between them and professionals. Goal setting by parents was aimed at empowering professionals with new knowledge and skills about ASD. The focus of parents was to make professionals appreciate why parents were lobbying for collaboration. During the workshop, professionals were made to share their challenges too and had to sympathise with parents' stories which they might have taken for granted of not allowing parents to voice their experiences about their child. The dialogue between parents and professionals created a relationship. Dempsey and Dunst (2004) suggest two forms of practical help: participatory and relational. Participatory practices take place when the affected group is involved in joint decision-making. Relational practices happen when professionals can give empathy and show support to parents. This happens when there is a professional-family relationship. Dempsey and Dunst (2004) further observed that both forms of help-giving practices appear to be associated with higher levels of parent empowerment.

Therefore, the parents-professionals partnership appears to lead to a multi-disciplinary collaboration among professionals. A classic example of a multi-disciplinary collaboration is when professionals such as psychologists, occupational and speech therapists, paediatricians, special teachers, and mainstream teachers work as a team to plan and develop strategies on how to assist both the child and parents. In the current study, parents reported having challenges to benefit from a multi-disciplinary team because such teams hardly exist, and professionals are not aware of ASD. However, when parents were planning the workshop, they specifically put together a team of professionals thus in essence creating their multi-disciplinary team. During the workshop, parents benefited from the knowledge gained from different professionals who presented their work on various topics (see chapter six). These parents decided to share their new knowledge by empowering the less empowered professionals and community members.

7. 4 Action 4. Lift as you rise

In the previous section, I talked about how the parents were able to empower each other with knowledge and skills with the support of ASD skilled professionals. In this section, parents now use their acquired knowledge to empower both professionals and fellow parents who were less empowered about ASD in rural settings. "Lift, as you rise" simply means that when you have opportunities and privileges in life, it is important to plough back your knowledge, skills, and

resources to the community where you came from. Participants in the current study did not want to leave anyone behind in their community regarding barriers to accessing ASD services. The idea of not leaving anyone behind is in line with the United Nations Sustainable Development Goals and the Zambian Seventh National Development Plan (The Government Republic of Zambia, 2017; United Nations, 2015) which advocate for total participation of all members in social change.

It appears that parents in this study were more concerned about the continued social stigma and discrimination in the community among fellow parents in more disadvantaged rural places. Parents saw it prudent to mitigate such a barrier by empowering the less empowered fellow parents and professionals with information about what ASD is, its causes and treatment, which helped address stigma against ASD children. Literature shows that social stigma and discrimination disempower parents (World Health Organisation (WHO), 2011,2015). This can imply the social welfare of the children with ASD and parents as they are likely to be denied access to goods and services (Kinnear et al., 2016). It is, therefore, the task of empowered parents to take up the responsibility of working towards reducing stigma and discrimination in their respective communities. This is because stigma and discrimination are a global phenomenon affecting mostly lower and middle-income countries (Divan et al., 2021; Dudley et al., 2019; Tekinarslan, 2018).

Stigma and discrimination can reduce by uplifting others through advocacy and transmitting such knowledge from one generation to the other. African traditional education system of passing values and beliefs from one generation to the other (Snelson, 1974) is one of the ways of mitigating stigma and discrimination in communities that are largely a collectivist society and believes in community responsibility in raising a child (Awopegba et al., 2013; Mbiti, 1969). If correct information about ASD is transmitted from one generation to the other through stories, customs and beliefs, this would reduce stigma and discrimination in the community.

However, in this thesis, it was observed that, despite Zambians practising collectivist way of living, members of the community did not provide adequate support in assisting parents to manage challenges that come with caring for a child with ASD. Parents complained that the community was less supportive, and members appeared to live their normal lives as if ASD parents did not exist in their communities. This negative attitude can be attributed to limited

knowledge by the local community about the causes, diagnosis, and treatment of ASD (Nyoni & Serpell, 2012). In addition, it appears there is a hegemony of Western capitalism developing among the new Zambian generation who value an individualist way of life as compared to the existing collectivist way of life. Westernisation as a way of life is slowly diluting the African culture (Sibani, 2018).

Despite Westernisation slowly creeping into the Zambia society, mostly in towns and among the educated, peer-parent support provides an opportunity for the less empowered group to develop growth on how to deal with barriers brought by having a child with ASD (Ainbinder et al., 1998). The peer support is consistent with the African Philosophy of *ubuntu ngumuntu ngabantu* - “I am because of who we all are” (Mugumbate & Nyanguru, 2013, p. 82). This shows that despite parents facing barriers to ASD services, they were thinking about uplifting the welfare of others. This African spirit illustrated the act of selfless leadership exhibited by the group. Parents in the study realised that they should not only up lift fellow parents but also teachers who spend much time with the child at school.

The study indicates that there were benefits of empowering the less empowered teachers. This is because schoolteachers and school administrators are better placed to advocate for ASD awareness during school meetings, lesson delivery and extra curriculum activities such as sports. Teachers are considered as gatekeepers of information and are instrumental in imparting knowledge and skills to learners (James-Traore et al., 2004) and the community. The teachers function as role models and are well placed to advocate for healthy school environments by coming up with empowerment programmes in their local communities (Henning & Khanna, 2016). In addition, teachers can guide ASD learners and parents about the available formal and informal ASD services. Therefore, teachers are required to be trained and be empowered with skills and knowledge about ASD. Parents in the current study observed that teachers had limited knowledge about ASD. Parents were aware that, if teachers are less empowered, there are higher chances of continued gaps in how ASD information is perceived by teachers and learners in schools. This was the reason that they had to empower teachers with knowledge and skills about ASD. In this study, it was not only teachers who needed empowerment but also other professionals such as health professionals.

Equally, there are benefits of empowering the less empowered community health workers (CHW). CHW are frontline workers who provide quality health care to the local community (The Government of the Republic of Zambia, 2012). These CHW who live in the same community with their parents can develop a close relationship with the local parents to whom they provide the services. This creates trust between health workers and the community, resulting in the parents easily accepting the recommendations that the health workers make regarding the cause of ASD, its diagnosis and treatment. It is against such a background that parents had to empower the less empowered CHW in their communities.

This section has revealed the value of uplifting others, particularly those who are less empowered. Empowering the community improves service delivery and enhances know-how about ASD. It also increases the power for the less empowered groups to make an informed decision about access to ASD services. It is against such a background that parents had to increase their empowering journey by taking the ASD awareness message to the broader community.

7.5 Action 5: Back to the roots: Creating ASD awareness in the broader community

In this final journey, parents as a support group still have more to do in terms of advocating for ASD awareness. Parents had to undertake a deep reflection about the empowerment journey from the first action cycle of forming parent-led support, later negotiating power imbalances with professionals, then empowering the less empowered fellow parents and professionals in their communities. Parents now had to deal with the ‘final piece of the puzzle’ that needed to be solved. This was creating awareness of ASD in the broader community. The puzzle was solved by first parents sharing their personal stories about what it means to be a parent of a child with ASD and secondly engaging journalists to cover their stories in newspapers.

The participants realised that knowledge is power. What is worth noting is that parents observed that the broader community in Zambia had limited knowledge and understanding about ASD (Chansa-Kabali et al., 2019). Therefore, there was a need to go back to the roots and take the awareness message to the broader community. The broader community includes celebrities, politicians, sportsmen and women and other individuals who may not be near the parents’ local community. These individuals hold high positions in society and may have influence in bringing

change at a broader level because of having a large following of people in society. These celebrities may also be role models in the community.

Parents in the current study saw it prudent to reach out to the broader community because the attitude of the community towards ASD services has a bearing on how parents can care for a child with ASD (Kang-Yi et al., 2018). In addition, any limited knowledge by the broader community put parents at higher risk of being discriminated against and marginalised by the same community (Kang-Yi et al., 2018). Therefore, having an understanding of ASD is critical as it helps the community to be aware of the many challenges parents of children with ASD face in accessing services (Divan et al., 2021). This helps reduce the negative attitude and myths the community may have about autism (Kang-Yi et al., 2018).

Parents in the study engaged the media to highlight their plight. The use of the media houses was appropriate because print media such as newspapers have wider coverage and readership (Bwalya, 2018). Parents shared their stories with the public and private press media houses about their lived experiences. These stories were published in Diggers Newspaper, a private individual owned newspaper (see Appendix T) and Daily Mail, a public newspaper. Participants had to engage the media to reach the broader community because there is the limited media coverage on issues of ASD by both private and public media houses from the Zambia context.

Many persons with disability got the information about health from health centers as compared to the media. In addition, there is a limited number of publications that have surveyed the level of coverage by the media on issues related to ASD. This contrasts with studies conducted in developed nations where, for example, Kang (2012) examined television news networks' coverage of autism in terms of issues, sources, and personal (episodic) or social (thematic) responsibility from the framing perspective. He did a content analysis on television news transcripts about autism from 1990 to 2010. The study by Kang (2012) revealed that the top three key issues identified that were covered during television discussions were personal story, child, and cause. The doctor was the most interviewed source, followed by the family and people with ASD.

The United Nations Convention on the Rights of Persons with Disabilities, (2006) urges its member states to raise awareness and combat stereotypes and prejudice associated with persons

with disabilities. There are limited studies in Zambia that have looked at media coverage of ASD. This is in contrast with the studies conducted in the United States of America (USA) where ASD was one of the widely covered topics by journalists (Kang, 2012). The media in Zambia need to cover ASD stories because this is a human rights issue as enshrined in the United Nations Convention on the Rights of Persons with Disabilities (2006). Previous studies indicate that empowering media houses about ASD issues increases the broader reflection by journalists and film actors about the causes, diagnosis and treatment of ASD (Belcher & Maich, 2014).

During the study, I observed that journalists who cover disability-related conditions such as ASD did it out of passion and not because the law compels them to do so. Literature has shown that the press is critical in the dissemination of information and helping to transform the community and making them understand some of the activities children with ASD are capable of doing, such as the love of watching television (Kuo et al., 2014) and the use of the internet. For example, the images and stories about parents of ASD in the media can influence the public perception and opinion about how ASD is perceived in society. Barnes (1991) acknowledges that the media influences the attitude and perception that society may have towards persons with disabilities.

The section has highlighted that how parents reached the broader community by sharing their lived experiences with journalists was one way of empowering the media houses and engaging them to publish the stories in the newspapers. The assumption of parents reaching out to the broader community was that there were higher chances that media house influence would increase and improve the positive image about ASD and decrease the stigma and discrimination that people with disabilities and their families face from the community.

7.6 Summary of the chapter

Chapter seven has highlighted how parents moved from disempowered groups to empowered individuals. This is the story of hope. The first empowerment journey started when parents formed a support group. It was through a support group that parents realised their first civic duty of electing leaders of their choice to lead them and be motivated to share advocacy messages, first among themselves and later with professionals. We see parents becoming experts of ASD whilst many professionals were viewed as novices. Parents were able to

dialogue with professionals and educate the professionals about ASD, while at the same time harnessing the skills of some knowledgeable professionals to increase their levels of knowledge and skill.

Parents recognised their potential and wanted professionals to consider them as equal partners. Later, parents took the awareness message to less empowered parents and professionals. The last puzzle in this chapter was how parents could reach the broader community. For instance, parents decided to go back to the broader community where they came from. To support this, parents engaged journalists and shared their stories that were published. Through the press, ASD messages reached a wider readership beyond the boundaries of Zambia.

CHAPTER EIGHT

PUTTING TOGETHER ALL THE STRANDS OF THE EAGLE'S NEST

8.0 Overview

Chapter eight is the last chapter of the thesis which is *putting together all the strands of the nest*. It gives a summary of the whole thesis. The chapter has three sections. Section one is about the implications of the thesis. In this section, I revisit the literature and provide a summary of the key findings in the study. I also interrogate the methodology and the theories used in the study. Section two gives my journal reflections. Section three discusses research recommendations, limitations, and the conclusion of the thesis.

8.1 Section one: Implications of the thesis

I begin this section by interrogating the implications of this study in relating to the current research findings as discussed in other related reviewed literature.

8.2 Revisiting literature to relate the previous findings to this study

A search for scholarly literature works in Zambia confirmed that this is the first study in Zambia that has explored the experiences of Zambian parents of children with ASD in accessing ASD services using PAR methodology. A few studies in Zambia have considered the experiences of parents of children with other disabilities (Chirwa, 2017; Macha et al., 2020; Nkhosi & Menon, 2015; Nyoni & Serpell, 2012; Washington-Nortey & Serpell, 2021; Wonani & Muzata, 2019). To have a deep insight into parents' unmet needs, I had to depend more on global literature as compared to studies conducted in Zambia. This was because of the limited publications in Zambia relating to ASD and parent support.

Reflecting on the key findings in this study, it was confirmed that, generally, parents of children with ASD in Zambia are a stressed group who have many unmet ASD needs for the child and themselves. These parents face varying challenges in accessing formal and informal ASD services. This is consistent with the global literature that confirms that parents of children with ASD are the most stressed group (Boshoff et al., 2018; Das et al., 2017; Goedeke et al., 2019; Washington-Nortey & Serpell, 2021; Wonani & Muzata, 2019) as compared to children without disabilities. The contributing factor to stress has to do with the burden of managing the behaviour of the child, poor communication skills (American Psychiatric Association, 2013),

coupled with limited knowledge by the community and professionals on the causes, diagnosis and treatment of ASD (Chansa-Kabali et al., 2019). Other contributing factors to stress in this study included juggling for multiple knowledge about ASD from different service providers, distance to centres where ASD therapy services are provided and negative attitude of both the community and professionals towards the child with ASD.

Overwhelming literature in Sub-Saharan African nations confirms similar findings of parents experiencing various barriers to access the services (Abubakar, Ssewanyana, & Newton, 2016; Bakare, Munir, & Bello-Mojeed, 2014; Nkole, 2017; Ruparelia et al., 2016; Wonani & Muzata, 2019). The limited knowledge and understanding of ASD are attributed to limited ASD awareness, and publications, and insufficiently skilled ASD professionals (Abubakar, Ssewanyana, De Vries, et al., 2016; Davids et al., 2019; De Vries, 2016; Ruparelia et al., 2016).

The current findings revealed that the majority of the participants-both parents and professionals had a challenge to explicitly define and explain the causes, diagnosis and treatment of ASD from a cultural context and in local familiar languages. This is because terms like 'neuro deficiency' are difficult to translate into local languages and are not found in local language vocabularies. For example, the term 'abnormal brain' in many Zambian local languages can be translated as a 'child whose brain functioning is not normal' (meaning the child is mad). This can result in the community misinterpreting the cause of ASD and associating it with witchcraft and demonic power (Gona et al., 2016; Oti-Boadi et al., 2020). Such stories came from professionals such as teachers, clinicians and even among church members. It was revealed, however, in the current study that despite Zambia being a Christian nation (The Constitution of Zambia Act, 1996b) and practising a collectivist way of life (Mbiti, 1969), the community could not support parents in respite care, resulting in parents being sole providers of care.

Reflecting on the stories by parents on what it means to be a sole caregiver reveals how distressing and burdensome it can be to have a child with ASD. However, it was observed that it was not intended for the community to depart from their collectivist way of life. The reason was that the majority of the community members and immediate family members did not know how to care for a child with ASD. This is because the behaviour portrayed by the child was

unique and surprising to the community. This is coupled with the myth that the cause of ASD has links to witchcraft and superpowers (Nyoni, 2011). It appears the community did not know whether ASD was congenital or not and whether it could be acquired through direct contact with the child or can be transmitted from one person to the other, hence the community, including professionals, could not provide respite care to parents to allow them to relax, refresh and live a life without the burdens of caring for a child with ASD. Social-emotional support to families from the community is critical. However, many families have limited education on how to assist the affected parents. The families and the community need to be educated on how to assist parents of children with ASD (Goedeke et al., 2019).

Despite parents being sole caregivers, we did not find any parents who took their children to foster homes because of the failure to care for their children with ASD. Even children whose parents were dead were taken care of by family members who included great-grandparents who were older than 80 years. These parents opted to take care of their children in their respective homes and suffer the pain alone than allowing their children to be raised by the government through the social welfare department. This is consistent with a study conducted in South Africa among persons with intellectual disabilities that confirms that many of the children with intellectual disabilities spend their lifetime being kept by caregivers (McKenzie, McConkey, & Adnams, 2013). The concept of a foster home is a foreign ideology and is a global North concept.

Formal and informal support services are required to minimise mental health problems (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Pruitt, Willis, Timmons, & Ekas, 2016; Samadi, McConkey, & Kelly, 2012; Weiss, Wingsiong, Lunskey, 2014). The support should come from both the community and professionals (De Vries, 2016; Wonani & Muzata, 2019). However, this study confirmed that Zambia has insufficient skilled ASD professionals to adequately provide the needed services. This is mirrored in many studies conducted in Zambia that confirm the insufficiency of health professionals in Zambia (Makasa, 2009; The Government of Republic of Zambia, 2014; The Government of the Republic of Zambia, 2012b). Stories of limited skilled professionals is a common phenomenon in Africa (Davids et al., 2019; de Vries, 2016). This has resulted in these professionals being overwhelmed with work since they do not only deal with ASD clients but even other general medical health impairments. Zambia

like many other African nations needs to invest in mental health human resources (Mwape et al., 2010; Ngungu & Beezhold, 2009) to mitigate the burden experienced by parents in accessing quality services. Studies have shown that mothers who enrolled in a healthy and healthy family project that educates and empowers mothers of children with disabilities to improve health behaviours indicated reduced mental stress in parents and improved health wellbeing and quality of life for both the child and mother (Bourke-Taylor, Joyce, Grzegorzyn and Tirlea(2021).

The burdens that parents identified made them act and empower themselves and the community on the need to advocate for ASD awareness in their respective communities. One of the steps taken by the parents in this study was to form a support group. It was through a parent-led support group that parents provided peer-to-peer empowerment, and later empowered specific professionals in higher learning institutions. These parents had also to address the power imbalances with professionals, empower the less empowered professionals and fellow parents in rural communities, and finally take the advocacy messages to the broader communities.

The study further has shown the benefits of using PAR in local communities affected by the challenges. The PAR process provides an evidence-based solution as participants owned the study and were able to negotiate their power balances with the community and professionals. Similar studies conducted by Kramer-Roy, (2007), Lorenzo, (2005), and Hope and Timmel, (1986) acknowledge the benefits of PAR methodology amongst Pakistani and families of children with ASD, South African mothers with disabilities and Zimbabwean communities respectively. The above summary confirms and disconfirms what the literature says in relation to the current findings.

I now discuss a reflection on the methodology and theories used in this study.

8.3 Methodological and theoretical reflections

In this study, it was essential to reflect on the methodology and theoretical frameworks used in this study.

8.3.1 Methodology perspective

The thesis used a qualitative PAR design. There were both negative and positive lessons learned during this study. Some of the challenging experiences were observed during data

collection. Organising the parents in the initial stage was time-consuming and I was filled with fear that parents might not turn up in large numbers during each action learning meeting considering that some were working parents and others such as those in the informal sector had to survive by selling some vegetables and other smaller merchandise for them to feed the child with ASD and the whole family. (See Roman numeral xxviii - **My Traditional Statement of personal reflexivity**).

However, the use of the PAR approach was advantageous because participants expressed themselves on issues affecting them in their familiar languages where participants could easily relate their experiences to their local environment (Leedy & Ormrod, 2010). The use of PAR allowed made me to wear different hats during data collection.

8.4 Section two: Reflecting on my journeying of wearing different hats

In this section, I give a reflection on my experiences during data collection. I reflect on how the “self-works, and how others are implicated by the self and the self’s desires, but also on how we represent – in writing...” (p. 111). Self-reflexivity was important because it allowed me to conduct a self-evaluation about my values, actions, and beliefs, and how such factors had an impact on the research process (Berger, 2015; McDonald, 2013). It was through self-reflexivity that I was able to reflect on the implications of this research to me as a researcher and also to the research participants (McDonald, 2013). As I positioned myself both as a facilitator and co-learner, I was wearing a variety of hats. The first was that of a parent of a child with autism who was coming from a slightly privileged middle-class group. The second hat was one where I had both practical and theoretical knowledge about ASD through the training in Special Education and Psychology at first degree and master's level and was involved in disability assessment. The third hat was that of a policy maker in early childhood education. I was thus not sure how to position myself at times. Going through my journal field notes each day helped me clear my mind and position myself as more of a facilitator than the above positions. Table 8.1 illustrates my struggles during data collection.

The struggle within me.
<i>I struggle to let go and make parents take control of the activities in the initial stage. Despite parents choosing their leaders, I found myself still contributing to the discussion and trying to still take a leading role. I loved the firmness of the chairperson who is an Executive Director of an engineering company. He showed that he was controlling the activities and meetings. He was able to make more parents contribute to how the programs were to be undertaken. This helped to remind me of my role in this study. That is a co-learner and facilitator, not a leader.</i>

Figure 8-1: Wearing two hats : Journal note: Date: 23 August 2018

The journal notes above illustrate the value of using the PAR qualitative approach. Through PAR, I learned the power of co-learning with parents. As a co-learner, I become aware of my shortcomings, both as a parent and policymaker. This is because some of the parents had two children with ASD, were single mothers, or grandparents. Others were from rural settings. Such experiences were different from mine. Co-learning enriched my experiences on what it means to be a parent of a child with ASD as I was collecting the data. This also allowed me to reflect on the tools I used to collect the data.

8.4.1 Reflection on the data collection tools

The experience of action learning, reflective meetings and field trips, interviews, pair groups, brainstorming, and plenary sessions with parents for ten months was another learning experience. I came to realise that true knowledge regarding health matters and ASD support services is with parents who may live with a child for life time as compared to professionals who have only limited time to understand the behaviour of a child. I learned that the diagnosis,

treatment, and strategies used for therapy services should not only be accessed by the educated and rich people but all Zambians regardless of their status in society. Therefore, the use of the holistic approach was required where both professionals and parents could collaborate to find solutions to challenges affecting the child.

The local rich knowledge of the caregivers needs to be appreciated and be incorporated as part of finding a solution to research findings. This rich knowledge that parents have about their children is beyond academic degrees and more important than other academic papers that we strived to obtain. Local knowledge is lived experiences, practical knowledge, authentic and transformative to both parents and the researcher. Chapter six, Action Cycle 2, gives a practical example how parents became experts of ASD whilst professionals were novices. Professionals' levels of attention were high when seeing a child with ASD for the first time. This made them appreciate local knowledge. Table 8.2 gives a reflection of what I observed.

The power of personal narrative stories
<i>I have never seen such attention of participants immediately they saw the child with ASD. When I told parents about ethical issues involving the child. Parents said, to us, it's about our children and the pain we feel as we walk with these children in the community. We have had awareness meetings; we go with them to churches and yet you don't talk about ethics.</i> <i>As I was going driving home, I heard one parent saying: 'I was happy I came. I also learnt a lot. Our WhatsApp group had messages about what happened during the meeting informing other parents.</i>

Figure 8.2: The power of personal narrative stories: Journaling: 30 August 2018.

8.4.2 A reflection on how data was analysed

In many traditional types of research, mostly quantitative, it appears data analysis is one activity rather than an ongoing activity. In this study, data analysis was an ongoing process (Miles, Huberman and Saldana, 2020) from the planning stage to the end of the study. Each time I collected data, I had to reflect on the field notes and actions on the behaviour of the parents. Transcribing data was an emotional journey at times. I had to stop for over a month transcribing because the parents' stories were emotionally touching though very educative and insightful. I had to take breaks during transcribing to help digest the stories and remove my emotional experiences away from influencing the true meaning of the participants' stories.

Analysing data in qualitative PAR methodology provided an opportunity to have an in-depth understanding of ASD from a holistic approach. I gained knowledge from rural and urban parents, educated and uneducated perspectives, single mothers, couples, and professionals from various institutions. ASD skilled professionals equally narrated their emotional stories regarding the challenges they face when providing ASD services. I came to learn that when it comes to emotions caused by the child's behaviour, they affect both the educated and uneducated and are all affected in the same way and expressed in similar manner. Both educated and uneducated require formal and informal counselling services and parental support from the local community on how to care and manage the challenges that comes from a child with ASD.

During the data collection period, I was aware that I was dealing with an issue that was sensitive and evokes emotions of parents' past and present experiences with ASD. Therefore, I needed to be psychologically prepared during the facilitation of the activities. The research skills gained from the monthly series of seminars provided by the University of Cape Town Library and Department of Health and Rehabilitation and the PhD writing circle enhanced the skills on how to deal with challenges. Table 8.3 shows some of the experiences I went through as I was listening to stories of parents during data collection.

Mothers are strong.
<i>I am touched by the story of a great- great grandmother (Parent: FDG6 P4) who takes care of an ASD boy who is stronger her. She has come to the meeting despite a strained leg after she was pushed by him.</i>
<i>A single mother explained the challenge her child faces who can stay for three to four days without eating anything but only taking a sip of water. The mother explained that the child has sensory challenges with food.</i>
<i>Another single mother narrated the challenges she faced with her supervisor who could not understand her challenge with an ASD child. She had to request a departmental transfer because her previous supervisors could not understand her child's condition</i>
<i>My question was: What material are Zambian ASD parents made of that made them have such resilience?</i>

Figure 8.3: Illustrating parents as strong and resilient parents: Journal reflection. August 23, 2018.

The stories above illustrate the resiliency that parents exhibited as they raise a child with ASD.

8.5. Theoretical perspective reflexivity

At the theoretical level, I selected Bronfenbrenner Bio-ecological and system and Critical-emancipation. I observed that the theoretical frameworks selected were appropriate because they focused on the interconnectedness of parents and the community.

8.5.1 Bronfenbrenner Bio-Ecological System levels

The study has confirmed that the use of Bio-ecological systems shows how the environment has an impact on human actions and behaviours. This is consistent with studies on the

Bronfenbrenner Bio-ecological system levels (Bronfenbrenner, 2005; Rosa & Tudge, 2013). It has also shown how parents as an affected group can positively impact the environment to bring about community transformation on how ASD services are perceived. Furthermore, the theory has shown the need for both the community and parents to work as a team to overcome the challenges affecting the community such as limited ASD services and awareness.

The fear about the future of the child if he or she outlives caregivers' lives is an indication of the parents' level of attachment to the child, hence the desire for the local environment to provide support to both the child and parents.

This study has shown the need to empower parents at the micro-level. The support at micro level of Bronfenbrenner's ecological level should first focus on parent-to-parent support. The support should be provided by parents with similar experiences on how to care for a child with ASD or a disability. These parents should support each other at micro level before engaging the whole family. Many times, immediate family members may not have more knowledge about the child or on issues of disability but specific parents in the community at meso level may have. Such groups with knowledge need to be engaged to provide pre-counselling and support to parents with a child with ASD on how to care and manage a child at micro level. This can help parents have some knowledge on how to support each other. Therefore, parents need to have a strong connection at meso levels before they can empower the child and family members at the micro level.

According to the Bio-ecology theory, it advocates for parents to access information at the five ecological systems levels to assist in shaping behaviour and child development. This study has revealed that the interaction of parent-to-parent with similar challenges or agendas need to take a leading role in empowering the local community and professionals. The process should use the bottom-up approach to disseminate information. This means that when the community at various levels is empowered, there is likelihood of seeing social change in the society. Accessing information from people with similar situations seem to have worked well in this study.

8.5.2. Critical-emancipatory theory

The use of the Critical-emancipatory theory for ten months confirms that the Critical-emancipatory approach brings about social transformation in parents and the community (see chapter six). The emancipatory theory ignited in parents to first empower themselves with knowledge and skills and later expose social inequalities that exist in their community regarding access to ASD services. Parents realised that there will be little or no change in social injustices, discrimination, and inequalities if they don't actively get involved and voice out their concerns.

The Human rights approach seem to disempower the oppressed. The focus of the UN Human Rights policy contributors seems to target only the needs of the elite group and side-lines the oppressed, marginalised, and illiterate people. Therefore, the words of the oppressor "are emptied of their concreteness and become a hollow.... Verbosity" (Friere, 2005, p. 72). It appears that despite the UN Human Rights group urging its members to domesticate the documents, these documents are copied and pasted and still reflect the global North ideas on how to raise a child with ASD. This has increased the tendency to view all disabilities from the global North perspective and making them to be universal (Meekosha,2011). UN Human Rights are more about individualist life as compared to the collectivist way of living. Freire (2005) calls it the "banking" concept of education, in which the scope of action allowed to the students extends only as far as receiving, filing, and storing the deposits (Friere, 2005, p. 72). The study has shown that the fundamental human rights activities must be the ones that first critically-emancipate individuals, community-based, evidence-based, participatory, cost-effective, embracing, sustainable, giving a voice to a marginalised group, cultural context situated and issue-based.

The use of the Critical-emancipatory theory in this study has shown that human rights issues are not the reservoir of the elites and educated, but everyone and they need to speak the grassroots language. I agree with the position of emancipatory disability researchers (EDR) who states that EDR aims to expose social inequalities in the community (Henn et al., 2006). To the best of my knowledge, this is the first study in Zambia that has linked the Emancipatory Disability Research (EDR) to parents of children with ASD from the Zambian context. Parents were inclined to the disability motto of 'nothing about us without us'(Charlton, 1998). This

meant that there is nothing that can be achieved about the child with ASD without parents being involved. I further agree with Barnes who states that:

Emancipatory disability research is not about biology but commitment and researchers (with or without impairments) putting their knowledge and skills at the disposal of disabled people and their organisations, and the generation and production of accessible and useable knowledge (Barnes, 1992, p. 115).

Therefore, the involvement of the community in policy making at the grassroots level can help to quickly address social injustice in the community. It is the duty of the technocrats to translate the local knowledge into the policy language when drafting policy documents.

8.6. Transferring the PAR knowledge to my family empowerment

In this section, I now explain how I was empowered by this study. For example, each time we had reflective action learning meetings with parents, it was an opportunity to practice what I was facilitating. I transferred some of the lessons learned and practised them on my son with ASD and the family. This deepened my understanding of what it means to have a child with ASD. Figure 8.4: shows the reflective experiences from parents' stories to my home environment.

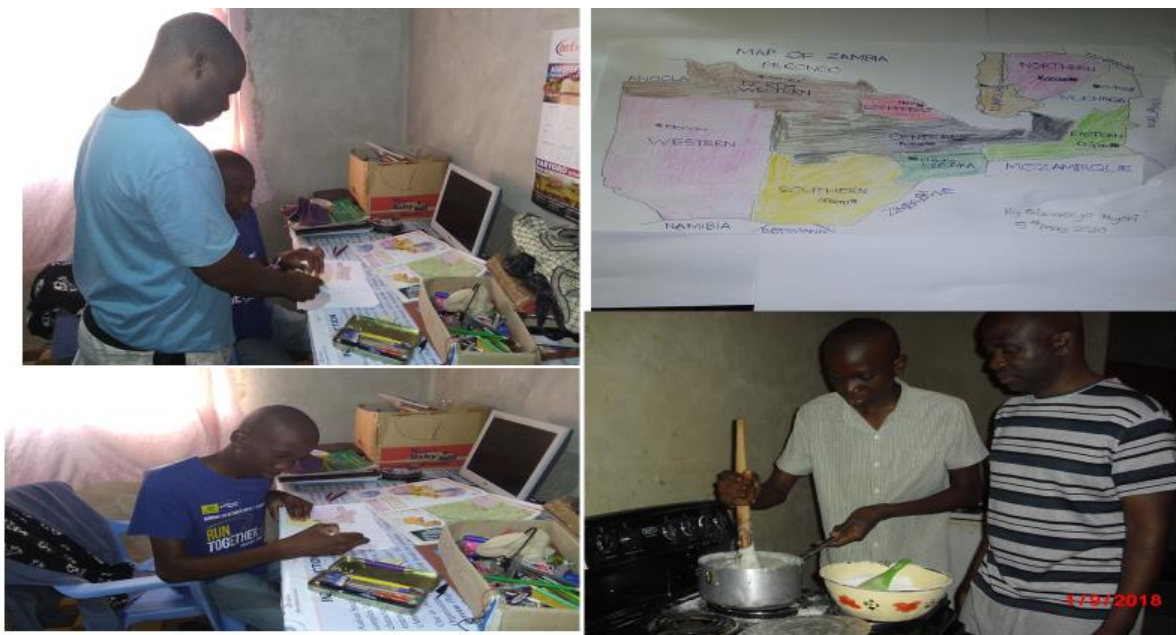


****Figure 8.4: Teaching my son survival skills**

** Figure 8.4: On the top right, the researcher is teaching the child how to draw the map. At the bottom left, the child draws the map of Zambia. The top right picture shows the completed map of Zambia. The last picture shows how the researcher was teaching the son the art of cooking Nsima. This is a Zambian traditional meal that is made of maize grain meal and thick porridge.

In this study, the meaning of participatory research was not only about the parents and the researcher. I also further involved my three sons in drawing the pictures used in this study. I have acknowledged my family support in the use of pictures they drew. This shows that this research was not only for my academic journey but part of therapy for the family too. As I transferred the knowledge to my family, I came to conclude that a family which is well informed and supportive to a child with ASD is a pillar of hope for the survival of a child with ASD. I came to learn from fellow parents that children with ASD are also religious in nature when introduced to it at an early stage of life. My personal experience has shown that children with ASD have their personal experiences about their own lives. Our son loves the following song: ***It is well with my soul****.

It is well with my soul

*When peace like a river attended my way
When sorrows like sea billows roll
Whatever my lot, Thou hast taught me to say
It is well, it is well with my soul*

Chorus

*It is well (it is well)
With my soul (with my soul)
It is well, it is well with my soul*

*Though Satan should buffet, though trials should come
Let this blest assurance control
That Christ (yes, He has) has regarded my helpless estate
And has shed His own blood for my soul*

*My sin, oh the bliss of this glorious thought (a thought)
My sin, not in part, but the whole (every bit, every bit, all of it)
Is nailed to the cross, and I bear it no more (yes!)
Praise the Lord, praise the Lord, O my soul!*

*And Lord, haste the day when my faith shall be a sight
The clouds are rolled back as a scroll
The trump shall resound, and the Lord shall descend
Even so, it is well with my soul!*

*Source: [Musixmatch](#). Songwriters: Traditional / Rice Christopher M

It Is Well With My Soul lyrics © Mercy Vineyard Publishing, New Fox Pico Songs Llc, T C F Music Publishing Inc

This song gives comfort to the whole family that *It is well with our child's soul* despite his condition. It also acts as a therapy for the family as it is one of the songs that gives hope to the hopeless or depressed family.

8.7. Section three: Limitations, recommendations, and conclusion of the study

Several recommendations can be made based on this study. Most recommendations are from the parents and professionals' views and reflections about barriers and hindrances to support services. This section provides the recommendation from the study and the research conclusion.

8.8 Practical research recommendations from the Zambian context

The recommendations are divided into two, general and specific. General recommendations are meant for all institutions, individuals and researchers involved in ASD provision whilst specific recommendations are targeting specific institutions.

8.8.1 General recommendations

The general recommendations are illustrated by pillars of hope which can be used by any institution or individual.

8.8.2 Ten pillars of recommendation to strengthen access to quality support services in Zambia

The following are the ten pillars of recommendation as shown in Figure 8.5.

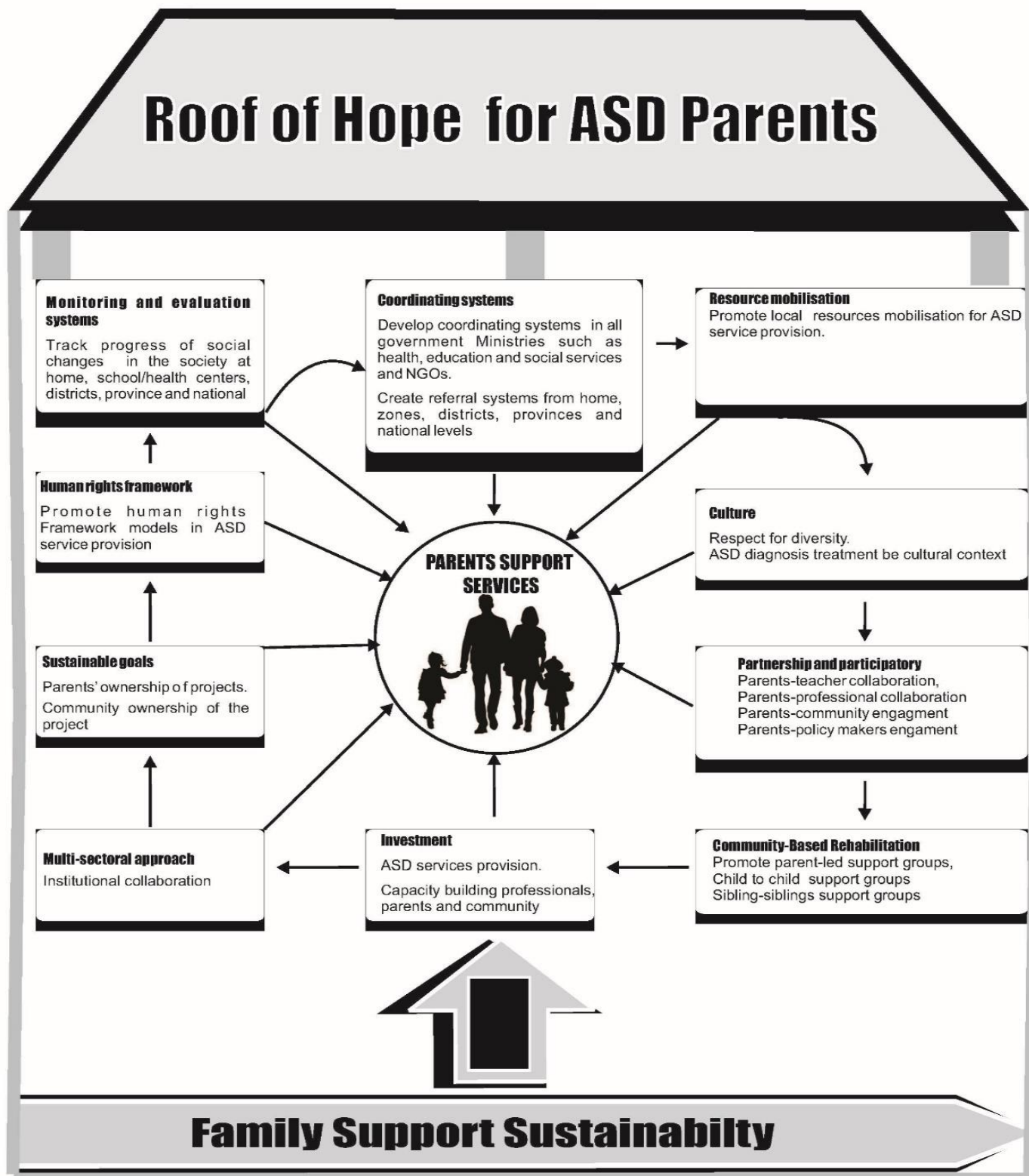


Figure 8.5 Pillars of Hope for a sustainable ASD programme in Zambia

Family support sustainability: The diagram above shows that all the ten pillars are anchored on the foundation of having family support that is sustainable to the parents and the child with ASD. In this study, the core unmet need for parents was the need to access support services (De Vries, 2016; Russa et al., 2015). The Government of the Republic of Zambia in line with the United Nations (UN) should develop affirmative actions that promotes the implementation of the UN set sustainable goals of ‘leaving no one behind’ (World Health Organisation (WHO), 2020). ASD support programmes should have an affirmative action policy for future sustainability. I recommend that the foundation of parents support groups should be anchored on a community-based rehabilitation programme (World Health Organisation (WHO), 2010) where the community own the project (Kramer-Roy, 2007; Lorenzo, 2005) and researchers become learners and not co-learners. Researchers need to learn from local people and not only become co-learners. The knowledge is with local people and not researchers. All activities must target parents. Therefore, I recommend that all ASD activities should not be conducted in isolation but must be interconnected and should follow a community family-based model that can be sustained.

Pillar one - Coordinating systems: Zambia needs to develop a coordinating mechanism on how ASD services must be provided at the national, provincial, district, zone and even at the village level. Civic and religious leaders, teachers, nurses, and prominent members in the community should be part of the ASD implementation coordinating system. The Seventh Nation Development Plan advocates for a multi-sectoral approach to service delivery (The Government Republic of Zambia, 2017). The coordinating systems that need to be developed should ensure that the right focal point persons who have knowledge about ASD are appointed to help in developing the ASD referral system from the local community to the national level.

Pillar two - Resource mobilisations: One of the greatest challenges to support services is inadequate resources (The Government Republic of Zambia, 2017). Currently, no budget specifically addresses autism-related issues for both the child and the parents. Parents as an affected group should be at the forefront to advocate for budget inclusion in autism-related programmes. This should be followed by resource mobilisation from NGOs, government, individuals, and other stakeholders. For example, the parents can lobby government to impose a 2% levy on all harmful products such as alcohol and cigarettes to go towards supporting the welfare of a child with autism and the parents.

Pillar three - Cultural diversity: The community needs to be educated on the need to respect diversity in the community. The community must be made aware that we cannot all be the same. Therefore, parents and other stakeholders must promote social acceptance of diversity in the community. Cultural diversity should be practised during service provision and professionals need to understand and appreciate the culture of parents of children with ASD when providing the services.

Pillar four - Partnership and participation: There is a need to promote stakeholders' participation partnerships with parents and their children with ASD. Autism NGOs and community-led parent support groups need to engage in partnership with other parent-led support groups in other communities within and outside Zambia to share resources and knowledge on how to support a child with ASD. The relationship that parents develop with stakeholders should aim at promoting activities that are evidence-based and can benefit the parents of children with ASD.

Pillar five- Investment: Zambia needs to invest in human resource development in the areas of health, education and social welfare services (The Government Republic of Zambia, 2017). There are few skilled professionals in Zambia who provide ASD services. In this study, it was observed that in Zambia there was only one neuro-paediatrician and less than 20 occupation therapists. No data shows any media houses that have journalists who have studied ASD and have vast knowledge to report and write in-depth stories about ASD. There is a need for the government and the public and private sectors to invest in professionals who are skilled in ASD. These professionals will be able to understand and appreciate children with ASD.

Pillar six- Multi-sectoral approach: The next pillar of hope is for the government to promote a multi-sectoral approach on how ASD service must be provided. This is in line with the seventh national development plan (The Government Republic of Zambia, 2017). The use of a multi-sectoral approach in dealing with ASD is critical. This will help parents to access services from different professionals and sectors. For example, if government line ministries such as Education, Health, Social Welfare Services and Finance can work as a team, there are higher chances of all line Ministry officers understanding what ASD is. This can result in line ministry officers developing policies that can benefit the child and parents. The approach will also cut out red tapes during service provision.

Pillar seven - Implementing United Nations Sustainable Goals: All stakeholders in Zambia must invest in goals 3, 4 and 10 of the United Nations (World Health Organisation (WHO), 2020). This will help the government track its progress on whether Zambia is meeting the target set. Secondly, investing in the UN sustainable goals will also help improve the lives of both the parents and children with ASD. Implementing sustainable goals further promotes transparency on how services are provided. Transparent will be observed by the community as the government will be able to provide statistics and any other achievements done towards the goal set. These goals can mostly be achieved when parents as the affected group take ASD advocacy as one of the priorities to service delivery.

Pillar eight - Human rights framework: There is a need to develop human rights framework that promotes equality for all and supports families of children with ASD to access quality services. Access to services is part of human rights. It must not be reserved for only the educated and rich. Issues of equity need to be promoted by all Zambians. The rights of children with ASD should not be suppressed or undermined by anybody or institutions. Human rights activists such as lawyers, singers, preachers, sports personalities should be in the lead to promote the rights of parents and children with ASD.

Pillar nine - Monitoring and evaluation systems: We need to invest in tools for monitoring and evaluating ASD diagnosis, treatment, and therapy services. A tracking system can be created to monitor how parents of children with ASD can access services, manage stress, mobilise resources and access the nearest parent-led support group. An ASD computer software application can be developed to document and capture how parents are currently coping with caregiving for a child with ASD. Community health workers and nurses can be trained on how to identify and track early symptoms of ASD before the child is referred for further investigations. Community health workers in their local zones can track the progress of social changes in society about ASD. Such information can be used in the database to understand the levels of community awareness and the type of support provided to parents of children with ASD.

Pillar ten - Roof of hope: It is the desire of each person to be under a roof that provides hope in areas of access to support services, emotional and social support. Immediate family members, siblings and the spouse need to provide the support to the child. I recommend that the whole household needs to be empowered on how to support a child with ASD. The house should provide hope to the child and parents by providing support to them. Creating awareness

for the family is critical as it helps them to protect the child from discrimination and abuse by the community. The house needs to provide warmth to parents to avoid increases of stress.

8.8.3. Specific recommendations for institutions

I further recommend the following steps to be considered:

8.8.3.1. Increasing ASD awareness in the broader community

There is a need to promote ASD awareness campaigns in churches, schools, hospitals, media houses, NGOs, and communities. This can be done through flyers, billboards, use of drama, appointing ASD ambassadors and utilising the month of April to promote ASD awareness countrywide.

8.8.3.2. Education Sector: Revisiting how education is provided to ASD children

Currently, the type of education provided to Zambian children with ASD is so stressful and traumatising to parents (See chapters five and six). The Ministry of Education should take the following steps to improve access, quality, equity, efficiency, and effectiveness of education to children with ASD:

1. Design curriculum and programmes on ASD from early childhood education to higher learning institutions. The Ministries of Education and Social Services should develop robust programmes that can use student teachers as respite care service providers to parents. This will help parents have time for leisure and plan their lives away from the child with ASD. The use of students as caregiver aids can be cheaper because students can be engaged during their teaching experiences for trainee teachers and interns and to acquire practical skills for other professionals. This can add to their examination results to make them more practical.
2. The national examination should not rely on centralised predetermined curriculum targets. It should allow individualised child tailored and flexible examinations where learners can use multiple ways of expressing their knowledge and skills. A policy should be established where children with neuro challenges and other disabilities that impede them to write exams, but they can answer questions set, then some can write on their behalf.
3. Learners with ASD should have an option to choose whether to access the mainstream curriculum or a child tailored one. This can be done after assessing the child to know whether he or she can cope with the mainstream curriculum.

4. I recommend that progression to the next Grade at 7, 9 and 12 should be based on the child's potential and not on mainstream curriculum which demands a learner to pass in six subjects at Grade 7, 9 and 12 level before progressing to the next grade. Some children with ASD are good at computers, music, sports, and art. (Emotional intelligent domains). Such children can be examined only in such fields and progress to the next grade rather than the six subjects which are hardly modified when teaching them.

5. The Examination Council of Zambia needs to revisit the policy of forcing learners with intellectual disabilities and hyperactivity to write the examination within a stipulated time of 2-3 hours with only an allowance of additional 30 minutes. Such children may not manage to sit for 10 minutes and yet they are forced to be in one place for over 2-3 hours. I recommend assessment should be a continuous process rather than a one-day activity. It is difficult to assess such children who may develop phobia with a new environment or being supervised by an unfamiliar person who never taught them.

6. Scientists must revisit their approach to African traditional education regarding issues of health and the use of indigenous knowledge. They need to invest in Afrocentric onto-epistemology. They are many lessons that were gained in this study regarding disability and traditional education that could be incorporated into modern science. See the stories in chapter six, Action Cycle 3). I recommend further studies into integrating African traditional knowledge in the search for an ASD cure and treatment.

7. There is a need to develop a training manual for students, professionals and primary caregivers and siblings and family members about ASD, its cause, diagnosis, treatment, child management and referral systems.

8.8.3.3. Health sector: Need for a paradigm shift on how health services are provided to ASD children

1. Diagnosis and management of ASD: There is a need for professionals to be trained on how to diagnosis ASD by developing tools that are standardised, culturally friendly and sensitive towards the needs of the parents and the child.

2. Curriculum content: The content in the curriculum in health institutions in Zambia needs to be strengthened. There is a need to introduce programmes at undergraduate to PhD level that promote research in the field of ASD. The Ministry of Health needs to construct a child

psychiatrist hospital or central to deal with a child psychiatrist and neuro paediatric. This will assist in the early identification of ASD.

3. Decentralised ASD diagnosis, treatment, and management: There is a need to decentralise how ASD services are administered. The Ministry of Health needs to have ASD qualified personal at all the levels of their service provision structure. The Ministry of health referral system needs to be followed which starts at health post to level three hospital. At each level, there is a need to have qualified professionals.

4. Decolonising the ethics clearance: In this study, I observed the challenges that African disability scholars face in conducting PAR disability research using the Western scientist space on issues of ethics and methodologies. I observed that there is a tendency by Western-oriented scholars to remind African scholars that they are writing their paper for an international audience (Meekosha, 2011). The international audience is the global North. This has normally made disability studies in the global South continue to be invisible (Nguyen, 2018). One of the challenges is the disability cultural space on issues of confidentiality. I observed that in the African communities, they believe in sharing challenges. This is because the child does not belong only to one parent but the whole community (Mbiti, 1969). The question that begs further investigation is from whose perspective should disability and ethics clearance be viewed during data collection? If participants believe in transparency when discussing the challenges, should a researcher impose his or her position when it comes to issues of advocacy for the sake of maintaining confidentiality? From whose lenses should ethics issues be understood and defined? Does modern ethics clearance take into consideration how African culture may want ethics and confidentiality defined? I observed that the ethical issues are based on the Western and medical approach which is biased towards the global North and does not take into consideration the African culture when it comes to disability studies.

My claim is that the use of a collective approach to the problem affecting the community through a participatory community-based approach provides a better option for parents to express their problems and resolve their challenges. I observed that during action cycle activities, parents were more concerned with finding a solution to the challenge affecting them rather than focusing on who is going to share their stories with others. I also observed there are some cultural norms of the society which are embedded in the culture regarding which information is considered confidential and cannot be shared with the community before the

right time, for example, the time for the marriage ceremony. Therefore, there is a need for researchers conducting studies in Africa to engage the community on the issue of confidentiality before carrying out a study as opposed to having an assumption that all disability topics may require ethics consideration from a Western space. I recommend that there is a need to have a pre-ethics clearance from the community that may act as a basis for medical ethics clearance.

8.8.3.4. Social welfare Sector: Promotion of equity

The Ministry of Social Welfare where disability issues fall needs to be more proactive in promoting the rights of children with intellectual disabilities as compared to investing only in physical, visual, and hearing impairments. I recommend the following:

1. Appointing focal point persons: The Ministry of Community Development should have a desk officer to spearhead ASD programmes. The focal point will be the one to advocate for the rights of both the child and parents. This is because caring for a child with ASD is more expensive than for any other disabilities.
2. ASD specific budget allocation: Developed nations provide some funds towards children with ASD. There is a need to have a budget to cushion the financial burden of caring for a child with ASD.
3. Invest in social workers: Government need to train social workers who will be able to work with both parents and children with ASD. These workers need to know about ASD.

8.8.3.5. Traditional healers

1. Incorporating their services: More research is needed on how the services of alternative medicine can be incorporated into current studies about the cure for ASD.
2. Capacity building: Traditional healers need to be educated about the cause of ASD.

8. 8.3.6. Religious leaders

Improve curriculum content: There is a need for the curriculum for training of clergy incorporate issues of disabilities such as ASD. Members of religious organisations need to be educated on ASD. Religious organisations need to develop programs that meet the needs of children with ASD and their parents.

8.9. Limitations of the study

The study had several limitations. Initially, my original intent was to include participants from remote and hard to reach districts of Luangwa and Rufunsa districts. However, I could not find parents of children with ASD medically certified. This narrowed the study recruitment to rural districts that are near urban settings. Narrowing the study made it easier to recruit 76 participants from both rural and urban settings who are closer to available ASD services in Zambia.

One of the key limitations was that most of the parents who were recruited had some formal of education and lived closer to urban districts where ASD services are provided. These parents may have had access to some training on ASD as compared to those who live in remote and hard to reach areas. This left the gap on the reality of parents of being a parent of a child with ASD living in remote and hard to reach areas. The parents in hard and remote areas may have a very strong traditional beliefs system with regards to causes and cure of disabilities.

Another limitation of the study was that I did not re-assess the children with ASD. All the information about parents was based on the reports provided by ASD assessment centres and special schools. However, some parents came with their medical reports showing that their child was on the spectrum. Therefore, I did not know the level on the spectrum of each child since it was not indicated on the child's documents.

I observed that some of the parents had limited knowledge on how to access online support groups. This made it difficult to gain knowledge on how illiterate parents or those unable to utilise technology could benefit from online support groups. Training parents on information technology would help understand the benefits of online support to all groups.

Given my personal and professional experiences as a parent of a child with ASD, researcher bias was acknowledged as a potential limitation of the study. To control for bias, I engaged in bracketing by journaling my thoughts, beliefs, and any prejudgments.

The other limitation I would like to acknowledge is that the fact that reflection meeting from one cycle and planning of the meeting for the next cycle often happened within one meeting and this may be a limitation.

This study was conducted during the rainy season. Some parents could miss the meetings because of the rains. The outbreak of some water borne diseases such as Cholera in Lusaka

Province delayed data collection, and this made some participants avoid attending meeting for fear of their health. This might have psychologically affected some parents who had some of their community members, relatives and friends might have been affected by Cholera outbreak. There is a need to conduct such studies immediately after the rains and before parents' start farming activities (April- August) would help.

However, the strength of this study was that the use of member checking where I first had to interview professionals on barriers to support services and later, they had to meet and share their experiences with parents was one way of collecting rich data for Phase two. In Phase one both parents and professionals shared their lived experiences about what they thought both knew about ASD services and yet they did not know until they shared their stories. Later in Phase two parents had to share their stories with specific professionals and later negotiated the power imbalances that exist between them when providing the services. I can finally state that most of the the assumption I had about parents and professionals' knowledge of about ASD as discussed in the preamble of this study were confirmed as correct.

The other strength was that the group was heterogeneous; it had parents from different backgrounds both rural and urban, old, and young, educated, and uneducated. Such information was rich to both the parents themselves and other participants who were empowered with advocacy messages from the support group.

8.10 Future research study areas

All parents in this study had a child who was going to school or was once in school. There is a need to investigate parents whose children have never had access to school.

This study was only conducted among black Zambians, and it was difficult to recruit other ethnic groups such as Zambians of Asian descent and whites. The few Asian parents I contacted were not willing to join other parents. It appears there is limited social interaction between black Zambians and Zambians of Asian origin. Research is needed on other ethnic groups such as Zambian Asian origin, whites and immigrant parents settled in Zambian and those in a refugee camp.

This study may not be generalisable because of its small sample that was confined to Lusaka Province. There is a need for future researchers to conduct a national survey to know the prevalence rate of ASD.

Other research areas of interest will include:

- Investigating whether there is a correlation between poverty and neurodevelopment in a child with ASD in Zambia.
- Investigating the role of parents in brain stimulation and behaviour change in ASD children using locally available materials.
- Employment opportunities for ASD children and their parents.
- Challenges parents experience as ASD children transit from one education sub-sector to the other.
- The next action cycle is needed to sustain the empowerment of parents. I recommend further studies on how best to facilitate family-professional relationships and ASD home-based programmes.

8.11. Conclusion of the thesis

This qualitative PAR study aimed to explore and understand the perceptions and lived experiences of parents of children with ASD in accessing ASD services in Zambia. This thesis contributes to new knowledge through the combination of theories and practice to better understand the experiences of parents of children with ASD within the Zambian cultural context.

According to this study there is limited knowledge and understanding of ASD from professionals, traditional healers, religious leaders, and the general community. This has impacted access to needed services by ASD parents. Another finding was that parents narrated that raising a child with ASD in Zambia is more stressful and fatiguing because of discrimination from the community. Many parents had to stop attending social events because of discrimination from the community. There is also limited awareness about ASD in the community, there is no financial support from the government and no budget line specifically for ASD. This means that parents use their own money to access the services such as medical bills and school tuition. This makes parents live isolated lives. Parents also required formal and informal support services.

The study has shown that the use of parent-led support groups provides the needed empowerment to parents through action reflective meetings and field trips where parents shared their stories with others. The use of teamwork was beneficial to all parents even those who

may not have had the courage to conduct advocacy activities as an individual before joining the support group.

To mitigate such barriers to support services. The study has shown how participants identified their challenges and formed a parent-led support group. Through the support group, parents were able to identify their problems, plan, act and evaluate their activities through action-reflection meetings.

More studies are needed in this field of ASD, as the condition has to be known and be accepted as part of human life. A Chichewa proverb says that ***chaona muzako chapita mawa chiliri pa iwe*** (The problems that your friends experience today are gone but tomorrow it could be you and maybe worse than them). This simply means that our future research studies should be aiming to resolve human problems before they hit us or one member of our closed community. In conclusion, disability and health rehabilitation studies should not be about personal agenda but the collective community agenda and should aim at emancipation, social change and social justice. The battle of increasing disability visibility mostly ASD is not for the faint but the strong researchers who do studies not for academic purposes only but for social change.

REFERENCES

- Abubakar, A., Ssewanyana, D., & Newton, C. R. (2016). A systematic review of research on autism spectrum disorders in Sub-Saharan Africa. *Behavioural Neurology*, 1–14. <https://doi.org/10.1155/2016/3501910>.
- Abubakar, A., Ssewanyana, D., de Vries, P. J., & Newton, C. R. (2016). Autism spectrum disorders in sub-Saharan Africa. *The lancet. Psychiatry*, 3(9), 800–802. [https://doi.org/10.1016/S2215-0366\(16\)30138-9](https://doi.org/10.1016/S2215-0366(16)30138-9).
- Adler-Baeder, F., Garneau, C., Vaughn, B., McGill, J., Harcourt, K. T., Ketrings, S., & Smith, T. (2018). The effects of mother participation in relationship education on coparenting, parenting, and child social competence: Modeling spillover effects for low-income minority preschool children. *Family Process*, 57(1), 113–130. <https://doi.org/10.1111/famp.12267>.

- Adom, D., Hussein, E. K., & Joe, A-agyem. (2018). Theoretical and conceptual framework: Mandatory ingredients of quality research. *International Journal of Scientific Research*, 7(1), 438–441.
- Ainbinder, J. G., Blanchard, L. W., Singer, G. H. S., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology*, 23(2), 99–109. <https://doi.org/10.1093/jpepsy/23.2.99>.
- Algood, C. L., Sung, J., Gourdine, R. M., & Williams, A. B. (2011). Children and Youth Services Review Maltreatment of children with developmental disabilities: An ecological systems analysis. *Children and Youth Services Review*, 33(7), 1142–1148. <https://doi.org/10.1016/j.childyouth.2011.02.003>.
- Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment*, 23(2), 126–136. <https://doi.org/10.1080/10911359.2012.747408>.
- Alsem, M. W., Meeteren, K. M. Van, Verhoef, M., Schmitz, M. J. W. M., & Jongmans, M. J. (2017). Co-creation of a digital tool for the empowerment of parents of children with physical disabilities. *Research Involvement & Engagement*, 3(1), 1-12. <https://doi.org/10.1186/s40900-017-0079-6>.
- American Psychiatric Association. (1987). *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed.). New York: American Psychological Association Inc.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) New York: American Psychological Association Inc.
- Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research : Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research & Policy Studies*, 5(2), 272–281.
- Anthony, B. J., Robertson, H. A., Verbalis, A., Myrick, Y., Troxel, M., Seese, S., & Anthony, L. G. (2020). Increasing autism acceptance: The impact of the Sesame Street “See Amazing in All Children” initiative. *Autism*, 24 (1), 95–108.

<https://doi.org/10.1177/1362361319847927>.

Appiah-Brempong, E., Newton, S., Harris, M. J., & Gulis, G. (2020). Effect of a theory-based hand hygiene educational intervention for enhancing behavioural outcomes in Ghanaian Schools: A cluster-randomised controlled trial. *International Journal of Public Health*, 65(1), 99–109. <https://doi.org/10.1007/s00038-019-01310-4>.

Armatas, V. (2009). Mental retardation: Definitions, aetiology, epidemiology and diagnosis. *Journal of Sport & Health Research*, 1(2), 112–122.

Atilola, O. (2014). Where Lies the Risk? An Ecological Approach to Understanding Child Mental Health Risk and Vulnerabilities in Sub-Saharan Africa. *Psychiatry Journal* (4):698348. DOI:10.1155/2014/698348.

Atilola, O. (2017). Child mental-health policy development in Sub-Saharan Africa : Broadening the perspectives using Bronfenbrenner's ecological model. *Health Promotion International*, 32, 380–391. <https://doi.org/10.1093/heapro/dau065>.

Audet, C. M., Gobbo, E., Sack, D. E., Clemens, E. M., Ngobeni, S., Mkansi, M., Aliyu, M. H., & Wagner, R. G. (2020). Traditional healers use of personal protective equipment: A qualitative study in rural South Africa. *BMC Health Services Research*, 20(1), 1–6. <https://doi.org/10.1186/s12913-020-05515-9>.

Awopegba, P.O., Oduolowu, E. A., & Nsamenang, A.B.(2013). *Indigenous early childhood care and education curriculum framework for Africa. A focus on Context and Contents*. Addis Ababa, UNESCO: International Institute for Capacity Building in Africa.

Babbie, E., & Mouton, J. (2012). *The practice of social research*. Cape Town: Oxford University Press.

Bai, D.; Yip, B.H.K.; Windham, G.C.; Sourander, A.; Francis, R.; Yoffe, R.; Glasson, E.; Mahjani, B.; Suominen, A.; Leonard, H.; et al. (2019). Association of Genetic and Environmental Factors with Autism in a 5-Country Cohort. *JAMA Psychiatry*, 76, 1035–1043.

Bakare, M. O, Ebigbo, P. O., Agomoh, A. O., & Menkiti, N. C. (2008). Clinical practice and epidemiology knowledge about childhood autism among health workers (KCAHW) questionnaire : description, reliability and internal consistency. *Clinical Practice and*

Epidemiology in Mental Health, 8, 1–8. <https://doi.org/10.1186/1745-0179-4-Received>.

Bakare, M. O, Ebigo, P. O., Agomoh, A. O., Eaton, J., Onyeama, G. M., Okonkwo, K. O., Onwukwe, J. U., Igwe, M. N., Orovwigho, A. O., & Aguocha, C. M. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BioMed Central*, 3, 1–13. <https://doi.org/10.1186/1471-2431-9-12>.

Bakare, M. O, & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, 14(3), 208–210. <https://doi.org/10.4314/ajpsy.v14i3.3>

Bakare, M. O., Munir, K. M., & Bello-Mojeed, M. A. (2014). Public health and research funding for childhood neurodevelopmental disorders in Sub-Saharan Africa: A time to balance priorities. *Healthcare in Low-Resource Settings*, 2(1), 1–9. <https://doi.org/10.4081/hls.2014.1559>.

Bang, M., Lee, S. H., Cho, S. H., Yu, S. A., Kim, K., Lu, H. Y., Chang, G. T., & Min, S. Y. (2017). Herbal medicine treatment for children with autism spectrum disorder: A systematic review. *Evidence-Based Complementary and Alternative Medicine*. <https://doi.org/10.1155/2017/8614680>.

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups*, 33(1), 69–83. <https://doi.org/10.1080/01609510903437383>.

Barnes, C. (1991). *Disabled people in Britain and Discrimination*, Hurst and Company, London

Barnes, C. (1992). Qualitative research: Valuable or irrelevant? Disability. *Handicap and Society*, 7(2), 115–124.

Barnes, C. (1999). A Working Social Model? Disability and Work in the 21st Century. *Disability Studies Conference and Seminar, 1999* (December), 1–27.

Barnes, C, & Mercer, G. (eds). (1996). *Exploring the Divide: Illness and Disability*. London:

The Disability Press.

Barnes, C. (2001). *Emancipatory Disability Research : Project or Process ?* (Issue Public Lecture at City Chambers, Glasgow, on 24 October 2001).

Barnes, C. (2003). What a difference a decade makes : Reflections on doing ‘emancipatory’ disability research. *Disability & Society*, 17(1), 3–17. <https://doi.org/10.1080/713662197>.

Baron-Cohen, S. (2015). Leo Kanner, Hans Asperger, and the discovery of autism. *The Lancet*, 386 (10001), 1329–1330. [https://doi.org/10.1016/S0140-6736\(15\)00337-2](https://doi.org/10.1016/S0140-6736(15)00337-2).

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Community Health*, 31, 854–857. <https://doi.org/10.1136/jech.2004.028662>.

Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography : Establishing “rigour” in interview analysis. *Royal Geographical Society*, 22, 505–525.

Belcher, C., & Maich, K. (2014). Autism spectrum disorder in popular media : Storied reflections of societal views. *Brock Education*, 23 (2), 97–115.

Bennett, T., Deluca, D. A., & Allen, R. W. (1995). Religion and children with disabilities. *Journal of Religion and Health*, 34 (4), 301–312.

Benson, P. R., Daley, D., Karlof, K. L., & Robison, D. (2011). Assessing expressed emotion in mothers of children with autism: the autism-specific five-minute speech sample. *Autism : The International Journal of Research and Practice*, 15(1), 65–82. <https://doi.org/10.1177/1362361309352777>.

Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219–234.

Blair, K.-S. C., Lee, I.-S., Cho, S.-J., & Dunlap, G. (2011). Positive behaviour support through the family-school collaboration for young children with autism. *Topics in Early Childhood Special Education*, 31(1), 22–36. <https://doi.org/10.1177/0271121410377510>.

Bless, C., Hingson-Smith, G., & Kagee, A. (2009). *Fundamentals of social research methods: An African perspective*. Cape Town: Juta.

- Boehm, T. L., & Carter, E. W. (2016). A systematic review of informal relationships among parents of individuals with intellectual disability or autism. *Research and Practice for Persons with Severe Disabilities*, 41(3), 173–190. <https://doi.org/10.1177/154079691665733>.
- Bölte, S., Mahdi, S., De Vries, P. J., Granlund, M., Robison, J. E., Shulman, C., Swedo, S., Tonge, B., Wong, V., Zwaigenbaum, L., & Segerer, W. (2019). The Gestalt of functioning in autism spectrum disorder : Results of the international conference to develop final consensus international classification of functioning, disability and health core sets. *Autism*, 23(2), 449–467. <https://doi.org/10.1177/1362361318755522>.
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents’ voices: ‘why and how we advocate’. A meta-synthesis of parents’ experiences of advocating for their child with an autism spectrum disorder. *Child: Care, Health and Development*, 1–14. <https://doi.org/10.1111/cch.12383>.
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). Parents' voices: “Our process of advocating for our child with autism.” A meta-synthesis of parents' perspectives. *Child: Care, Health and Development*, 44 (1), 147–160. <https://doi.org/10.1111/cch.12504>.
- Bower Russa, M., Matthews, A. L., & Owen-DeSchryvery, J. S. (2015). Expanding supports to improve the lives of families of children with an autism spectrum disorder. *Journal of Positive Behavior Interventions*, 17(2), 95–104. <https://doi.org/10.1177/1098300714532134>.
- Boyd, B. (2002). Examining the relationship between stress and lack of social support in mothers of children with Autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208–215. <https://doi.org/10.1177/10883576020170040301>.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism : The International Journal of Research and Practice*, 8(4), 409–423. <https://doi.org/10.1177/1362361304047224>.
- Brondino, N., Fusar-Poli, L., Rocchetti, M., Provenzani, U., Barale, F., & Politi, P. (2015). Complementary and alternative therapies for autism spectrum disorder. *Evidence-Based*

Complementary and Alternative Medicine, 2015. <https://doi.org/10.1155/2015/258589>.

Bronfenbrenner, U. 1979. *The Ecology of Human Development*. Cambridge, Mass.: Harvard University Press.

Bronfenbrenner, U. (1989). Ecological systems theory. In P. Vasta (Ed.), *Annals of Child Development: Vol. 6. Six Theories of Child Development: Revised formulations and current issues* (pp. 187-249). London: Jai Press.

Bronfenbrenner, U. (1994). Ecological models of human development. In *Readings on the Development of Children* (Vol. 3, pp. 37–43).
<https://doi.org/http://www.psy.cmu.edu/~siegler/35bronfebrenner94.pdf>.

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological Perspectives on human development*. London: Sage.

Bronfenbrenner, U., & Evans, G. W. (2000). Developmental science in the 21st century: Emerging theoretical models, research designs, and empirical findings. *Social Development*, 9, 115–125.

Bronfenbrenner, U., & Morris, P. A. (2006). *The Bioecological Model of Human Development*. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology, Vol. 1: Theoretical models of human development* (6th ed., pp. 793 – 828). New York: Wiley.

Bronfenbrenner, U., & Morris, P. A. (1998). *The ecology of developmental processes*. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology, Vol. 1: Theoretical models of human development* (5th ed., pp. 993 – 1023). New York: Wiley.

Brún, M. O. R., Brún, T. De, Okonkwo, E., Manuela, M., Silva, D. A., Ogbemor, F., Mierzejewska, A., Nnadi, L., Weel-baumgarten, E. Van, Weel, C. Van, Muijsenbergh, M. Van Den, & Macfarlane, A. (2016). Using participatory learning & action research to access and engage with ‘hard to reach’ migrants in primary healthcare research. *BMC Health Services Researsch*, 16(1), 1-16. <https://doi.org/10.1186/s12913-015-1247-8>.

- Buescher, V. S., Zuleyha, C., Knapp, M., & Mandell, D. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, 19104(8), 721-728. <https://doi.org/10.1001/jamapediatrics.2014.210>.
- Bwalya, E. M.M. (2018). Media as defender of the girl child in Zambia. *Journal of Advances in Social Science and Humanities*. 4 (10), 328-340, <https://doi.org/.15520/jassh410363>.
- Cameron, D. L. (2018). Barriers to parental empowerment in the context of multidisciplinary collaboration on behalf of preschool children with disabilities. *Scandinavian Journal of Disability Research*, 20(1), pp. 277–285. doi: 10.16993/sjdr.65.
- Caron, K. G., Schaaf, R. C., Benevides, T. W., & Gal, E. (2012). Brief report-cross-cultural comparison of sensory behaviours in children with autism. *American Journal of Occupational Therapy*, 66(5), 77–80.
- Carr, E. S. (2003). Rethinking empowerment theory using a feminist lens: The importance of process. *Affilia*, 18, 8-20.
- Carr, W. (2006). Philosophy, methodology and action research. *Journal of Philosophy of Education*, 40(4), 421–435. <https://doi.org/10.1111/j.1467-9752.2006.00517.x>
- Carter, I. (2009). Positive and negative experiences of parents involved in online self-help groups for autism. *Journal on Developmental Disabilities*, 15(1), 44–52.
- Centres for disease control and Prevention. (2020). *Community report on autism 2020*. In *Autism And Developmental Disabilities Monitoring Network*. <https://www.cdc.gov/ncbddd/autism/addm-community-report/documents/addm-community-report-2020-h.pdf>.
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- Chambers, R. (1994). The origins and practice of participatory rural appraisal. *World Development*, 22(7), 953–969. [https://doi.org/10.1016/0305-750X\(94\)90141-4](https://doi.org/10.1016/0305-750X(94)90141-4)
- Chambers, R. (2002). *Relaxed and participatory appraisal: Notes on practical approaches and methods for participants in PRA/PLA-related familiarisation workshops*. Participation Group, Institute of Development Studies, University of Sussex.

- Chansa-Kabali, T., Nyoni, J., & Mwanza, T. (2019). Awareness and knowledge associated with autism spectrum disorders among university students in Zambia. *Journal of Autism and Developmental Disorders*, 0123456789. <https://doi.org/10.1007/s10803-019-04044-7>
- Chaskin, R. J. (1999). *Defining community capacity: A framework and implications from a comprehensive community initiative*. Urban Affairs Association Annual Meeting, Fort Worth, April 22-25, 1998. Chapin Hall Center for Children at the University of Chicago.
- Chataika, T., McKenzie, J. A., Swart, E., & Lyner-Cleophas, M. (2012). Access to education in Africa: Responding to the United Nations Convention on the Rights of Persons with Disabilities. *Disability & Society*, 27(3), 385–398. <https://doi.org/10.1080/09687599.2012.654989>.
- Cheroni, C., Caporale, N., & Testa, G. (2020). Autism spectrum disorder at the crossroad between genes and environment: Contributions, convergences, and interactions in ASD developmental pathophysiology. *Molecular Autism*, 11(1), 1–18. <https://doi.org/10.1186/s13229-020-00370-1>.
- Chiluba, B., & Njapawu, W. (2019). Barriers of persons with physical disability over accessibility and mobility to public buildings in Zambia. *Indonesian Journal of Disability Studies*, 6(1), 53–63.
- Chirwa, M. (2017). *Experiences of parenting children with disabilities*. Unpublished thesis, Warwick University.
- Chitiyo, A. & Chitiyo, J. (2019). Autism in Zimbabwe: A brief review of trends, conditions, challenges, and intervention practices. *International Journal of Educational Research* 6(1) 50-59.
- Chitiyo, M., Kumudzro, F. K., Hughes, E. M. & Ahmed, S (2019). Teachers' professional development needs regarding inclusive education in Ghana. *International Journal of Whole Schooling*, 15(2), 53-79
- Clarke, V., & Braun, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Clifford, T., & Minnes, P. (2013). Who participates in support groups for parents of children

- with autism spectrum disorders? The role of beliefs and coping style. *Journal of Autism and Developmental Disorders*, 43(1), 179–187. <https://doi.org/10.1007/s10803-012-1561-5>.
- Cloete, L. G., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with an autism spectrum disorder in Kenya. *African Journal of Disability*, 8, 1–9. <https://doi.org/10.4102/ajod.v8i0.435>.
- Cohen, L., Manion, L., Morrison, K., Lecturer, P., Morrison, K., & Lecturer, S. (2007). Experiments, quasi-experiments, single-case research and meta-analysis. In *Research methods in education*. https://doi.org/10.1111/j.1467-8527.2007.00388_4.x
- Coolican, H. (2013). *Research methods and statistics in psychology* (5th ed.). New York: Hodder Education.
- Coleridge, P. (1993). *Disability, Liberation and Development*. UK: Oxfarm.
- Constitution of the World Health Organisation. (1945). Geneva: World Health Organisation.
- Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (4th ed.). London: Sage.
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, 41(12), 1667–1676. [https://doi.org/10.1016/0277-9536\(95\)00127-s](https://doi.org/10.1016/0277-9536(95)00127-s)
- Coulthard, P., & Fitzgerald, M. (1999). In God we trust? Organised religion and personal beliefs as resources and coping strategies, and their implications for health in parents with a child on the autistic spectrum. *Mental Health, Religion & Culture*, 2(1), 19–33.
- Cresswell, J. (2007). *Qualitative: Choosing among five approaches* (2nd ed.). London: Sage.
- Cresswell, J. (2014). *Research design: Qualitative, quantitative & mixed methods* (4th ed.). London: Sage.
- Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, 18(3), 213–222. <https://doi.org/10.1177/1362361312472261>.
- Cui, H., & Elizabeth, K. (2012). Evidence for a cultural influence on field-independence in

- autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(2), 181-190. <https://doi.org/10.1007/s10803-011-1232-y>.
- Dababnah, S., & Parish, S. L. (2013). “At a moment, you could collapse”: Raising children with autism in the West Bank. *Children and Youth Services Review*, 35 (10), 1670–1678. <https://doi.org/10.1016/j.childyouth.2013.07.007>.
- da Costa, G.E.; Fernandes, G.L.; Rodrigues, J.C.G.; da V. B. Leal, D.F.; Pastana, L.F.; Pereira, E.E.B.; Assumpção, P.P.; Burbano, R.M.R.; dos Santos, S.E.B.; Guerreiro, J.F.; et al.(2022) Exome Evaluation of Autism-Associated Genes in Amazon American Populations. *Genes* , 13, 368. <https://doi.org/10.3390/genes13020368>.
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with Autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266–280.
- Daley, T. C. (2002). Diagnostic conceptualisation of autism among Indian psychiatrists, psychologists, and paediatricians. *Journal of Autism and Developmental Disorders.*, 32, 13-23.
- Davids, E.L., Adams Tucker,L.A.,Wambua,G.N.,Fewster, D.L., Schlebusch, L., Karrim,S.B.S., Attia,M., Nyoni,J., Bayouh, F.G., Kuteesa, H., Brahim,T., Hoogenhout,M., Moussa Kahloul,R.M.,Jearey-Graham, N.,Gobie,H.B & Nalugya J.S., (2019) Child and adolescent mental health in Africa: A qualitative analysis of the perspectives of emerging mental health clinicians and researchers using an online platform. *Journal of Child & Adolescent Mental Health*, 31:2, 93-107, Doi: [10.2989/17280583.2019.1659145](https://doi.org/10.2989/17280583.2019.1659145).
- Das, S., Das, B., Nath, K., Dutta, A., Bora, P., & Hazarika, M. (2017). Impact of stress, coping, social support, and resilience of families having children with autism: A North East India-based study. *Asian Journal of Psychiatry*, 28, 133–139. <https://doi.org/10.1016/j.ajp.2017.03.040>.
- Dawson-Squibb, J. J., Davids, E. L., Harrison, A. J., Molony, M. A., & de Vries, P. J. (2020). Parent education and training for autism spectrum disorders: Scoping the evidence. *Autism*, 24(1), 7–25. <https://doi.org/10.1177/1362361319841739>.

De Grip, A., & Pleijers, A. (2019). Workshop Attendance as a Mode of Learning: Evidence from the Netherlands. *Vocations and Learning*, 12(3), 361–385. <https://doi.org/10.1007/s12186-019-09219-y>.

Dempsey, I., & Dunst, C. J. (2004). Help giving styles and parent empowerment in families with a young child with a disability. *Journal of Intellectual and Developmental Disability*, 1, 40–51. <https://doi.org/10.1080/13668250410001662874>.

De Vries, P. J. (2016). Thinking globally to meet local needs. In *Current Opinion in Neurology* (Vol. 29, Issue 2). <https://doi.org/10.1097/WCO.0000000000000297>.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. London: Sage.

Denzin, N., & Lincoln, Y. S. (2018). *Qualitative research*. London: Sage Publications.

DeThorne, L. S., & Ceman, S. (2018). Genetic testing and autism: Tutorial for communication sciences and disorders. *Journal of communication disorders*, 74, 61–73. <https://doi.org/10.1016/j.jcomdis.2018.05.003>.

Divan, G., Bhavnani, S., Leadbitter, K., Ellis, C., Dasgupta, J., & Abubakar, A. (2021). Annual

research review : Achieving universal health coverage for young children with an autism spectrum disorder in low- and middle-income countries : A review of reviews. *Journal of Child Psychology and Psychiatry*, 62(5), 514-535. <https://doi.org/10.1111/jcpp.13404>.

Dixon, M. R., Paliliunas, D., Barron, B. F., Schmick, A. M., & Stanley, C. R. (2019). Randomised controlled trial evaluation of ABA content on IQ gains in children with autism. *Journal of Behavioral Education*, 0123456789. <https://doi.org/10.1007/s10864-019-09344-7>.

Duckett, P., & Pratt, R. (2007). The emancipation of visually impaired people in social science research practice. *British Journal of Visual Impairment*, 25 (1), 5–20.

Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding

- service usage and needs for adults with ASD: The importance of the living situation. *Journal of Autism and Developmental Disorders*, 49 (2), 556–568. <https://doi.org/10.1007/s10803-018-3729-0>.
- Dunning, A. (1995). *Citizen to advocacy with older people: A code of good practice*. London: Centre for Policy on Ageing.
- Einfeld, S. L., Stancliffe, R. J., Gray, K. M., Sofronoff, K., Rice, L., Emerson, E., & Yasamy, M. T. (2012). Interventions provided by parents for children with intellectual disabilities in low and middle-income countries. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 135-142.
- Ekas, N. ., Tidman, L., & Timmons, L. (2019). Religiosity/spirituality and mental health outcomes in mothers of children with autism spectrum disorder: The mediating role of positive thinking. *Journal of Autism and Developmental Disorders*, 49(11), 4547–4558. <https://doi.org/10.1007/s10803-019-04165-z>.
- Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counsellors and other professionals. *The Family Journal*, 21(3), 279–287. <https://doi.org/10.1177/1066480713476834>.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13, 375–387. <https://doi.org/10.1177/1362361309105658>.
- Etteka, A., & Mahoney, J. (2017). *Ecological systems theory*. In *The Sage Encyclopedia of Out-of-School Learning* (Issue April, pp. 2–7). London: Sage. <https://doi.org/10.4135/9781483385198.n94>.
- Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the Human Sciences*, 26(3), 3–31. <https://doi.org/10.1177/0952695113484320>.
- Falk, N.H., & K., Quinn, M.G. (2014). The factors predicting stress, anxiety and depression

in the parents of children with autism. *Journal of Autism and Developmental Disorders*, 44, 3185–3203. <https://doi.org/10.1007/s10803-014-2189-4>

Fals-Borda, O. & M. A. Rahman, E. (1991). *Action and knowledge: Breaking the monopoly with participatory action research*. New York: Apex Press.

Faras, H., Al Ateeqi, N., & Tidmarsh, L. (2010). Autism spectrum disorders. *Annals of Saudi Medicine*, 30(4), 295–300. <https://doi.org/10.4103/0256-4947.65261>.

Fay, B. (1975). *Social theory and political practice*. London: George Allen & Unwin Ltd.

Fay, B. (1979). *Critical social science: Liberation and its limits*. London: Cornell University Press.

Field, S., & Hoffman, A. (1999). The importance of family involvement for promoting self-determination in adolescents with autism and other developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 14(1), 36–41. <https://doi.org/10.1177/108835769901400105>.

Fink, A. (2008). *Practising research: Discovering evidence that matters*. London: Sage.

Finkelstein, V. (1980). World Rehabilitation Fund, New York

Flick, U. (2014). *An introduction to qualitative research* (5th ed.). London: Sage.

Flick, U. (2018). *An introduction to qualitative research* (6th ed.). London: Sage.

Fong, E. H., & Lee, H. (2017). Sociocultural perspective on autism intervention. In *Sociocultural Perspective on Autism Intervention* (pp. 291–300). <https://doi.org/10.5772/65965>.

Franz, L., Carolina, N., Chambers, N., Isenbur, M., & De Vries, P.(2018). A comprehensive scoping review. *Autism Research*, 10(5), 723–749. <https://doi.org/10.1002/aur.1766>.

Franz, L., Chambers, N., von Isenburg, M., & de Vries, P.J.(2017). Autism spectrum disorder in sub-saharan africa: Acomprehensive scoping review.*Autism Research*,10, 723–749.

- Freire, P. (1968). *Pedagogy of the oppressed*. New York : Seabury Press.
- Freire, P. (1972). *Pedagogy of the oppressed*. New York: Penguin.
- Freire P., (1982). *Creating knowledge: A monopoly*. New York: Harper.
- Freire, P. (2005). *Pedagogy of the Oppressed*. New York & London: Continuum Publishing
- Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications. *Journal of Pediatric Health Care*. 30(5):453-63.<https://doi.org/10.1016/j.pedhc.2015.10.012>.
- Garbacz, S. A., McIntyre, L. L., & Santiago, R. T. (2016). Family involvement and parent-teacher relationships for students with autism spectrum disorders. *School Psychology Quarterly*, 31(4), 478–490. <https://doi.org/10.1037/spq0000157>.
- Garza, O. W. (2013). *An action research approach to examining perceptions and needs in diabetes care in a community in Mexico using the innovative care for chronic conditions framework and social capital theory*. Unpublished thesis. University of Iowa, Iowa. <https://ir.uiowa.edu/cgi/viewcontent.cgi?article=4847&context=etd>
- Geiger, D., Smith, D. T., & Creaghead, N. (2002). Parent and professional agreement on the cognitive level of children with autism. *Journal of Autism and Developmental Disorders*, 32(4), 307–312. <https://doi.org/10.1023/A:1016382819186>.
- Gernsbacher, M. A., Dawson, M., & Goldsmith, H. H. (2005). Three reasons not to believe in an autism epidemic. *Current Directions In Psychological Science*, 14(2), 55–58. <https://doi.org/10.1111/j.0963-7214.2005.00334.x>.
- Gilbert, N. (2008). *Researching social life* (3rd ed). London: Sage.
- Goedeke, S., Shepherd, D., Landon, J., & Taylor, S. (2019). Research in autism spectrum disorders how perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Research in Autism Spectrum Disorders*, 60(January), 36–47. <https://doi.org/10.1016/j.rasd.2019.01.005>.
- Gomes, P. T. M., Lima, L. H. L., Bueno, M. K. G., Araújo, L. A., & Souza, N. M. (2015). Autism in Brazil: A systematic review of family challenges and coping strategies. *Jornal de Pediatria*, 91(2), 111–121. <https://doi.org/10.1016/j.jped.2014.08.009>.

- Gona, J. K., Newton, C., Rimba, K., & Mapenzi, R. (2015). Parents and professionals' perceptions on causes and treatment options for autism spectrum disorders in a multicultural context on the Kenyan Coast. *PloS One*, 10(8), 1–13. <https://doi.org/10.1371/journal.pone.0132729>.
- Gona, J., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy*, 16(3517), 1–12.
- Gow, J., George, G., Mutinta, G., Mwamba, S., & Ingombe, L. (2011). Health worker shortages in Zambia: An assessment of government responses. *Journal of Public Health Policy*, 32(4), 476–488. <https://doi.org/10.1057/jphp.2011.41>.
- Grace, R., Hodge, K., & McMahon, C. (2013). *Children, families and communities*. Oxford: Oxford University Press.
- Gray, D.E. (2014). *Doing research in the real world*. (3rd ed.). London: Sage.
- Greenwood, D., & Levin, M. (2007). *Introduction to action research: Social research for social change*. (2nd ed.). London: Sage.
- Greydanus, D.E., & Toledo-Pereyra, L.H. (2012). Historical perspectives on autism: Its past record of discovery and its present state of solipsism, scepticism, and sorrowful suspicion. *Pediatric Clinics of North America*. 59(1), 1-11, ix. Doi: 10.1016/j.pcl.2011.10.004.
- Groce, N.E. (2004). Adolescents and youth with disability: issues and challenges. *Asia Pacific Disability Rehabilitation Journal*, 15 (2) pp. 13-32.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal*, 29(2), 75-91.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *Handbook of qualitative research*, pp. 163-194. London:

Sage.

Guler, J., De Vries, P., Seris, N., Shabalala, N., & Franz, L. (2019). The importance of context in early autism intervention: A qualitative South African study. *Autism*, 22(8), 1005–1017. <https://doi.org/10.1177/1362361317716604>.

Habermas, J. (1971) *Toward a Rational Society*. London:Heinemann.

Habermas, J. (1984). *The theory of communicative action, Vol.1:Reason and rationalisation of society*. Boston: Beacon Press.

Halwindi, H., Siziya, S., Magnussen, P., & Olsen, A. (2013). Factors perceived by caretakers as barriers to health care for under-five children in Mazabuka District, Zambia. *ISRN Tropical Medicine*, 2013, 1–10. <https://doi.org/10.1155/2013/905836>.

Hansen, A. M. W., Siame, M., & Van der Veen, J. (2014). A qualitative study: Barriers and support for participation for children with disabilities. *African Journal of Disability*, 3(1), 1–9. <https://doi.org/10.4102/ajod.v3i1.112>.

Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(11), 2604–2616. <https://doi.org/10.1007/s10803-013-1812-0>.

Harrison, A., Zimak, E., Sheinkopf, S., Manji, K., & Morrow, E. (2014). Observation-centred approach to ASD assessment in Tanzania. *Intellectual Development Disability*, 330–347. <https://doi.org/10.1352/1934-9556-52.5.330>.

Hartely, S., Murira, G., Mwangoma, M., Carter, J., & Newton, C. (2009). Using community/researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya. *Disability and Rehabilitation*, 31(6), 490–499. <https://doi.org/10.1080/09638280802061944>.

Hartley, S. L., DaWalt, L. S., & Schultz, H. M. (2017). Daily couple experiences and parent affect in families of children with versus without autism. *Journal of Autism and Developmental Disorders*, 47(6), 1645–1658. <https://doi.org/10.1007/s10803-017-3088-2>.

- Hastings, R. P., Robertson, J., & Yasamy, M. T. (2012). Interventions for children with pervasive developmental disorders in low and middle-income countries. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 119-134.
- Henning, M., & Khanna, S. (2016). Overburden, stigma, and perceived agency: Teachers as HIV prevention educators in urban Zambia. *AIMS Public Health*, 3(2), 265–273. <https://doi.org/10.3934/publichealth.2016.2.265>.
- Henn, M., Weinstein, M., & Foard, N. (2006). *A short introduction to social research*. London: Sage.
- Herbert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing*, 33, 149–163. <https://doi.org/doi:10.3109/01460862.2010.498331>.
- Hodgetts, S., Nicholas, D., & Zwaigenbaum, L. (2013). Home sweet home? Families' experiences with aggression in children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 28(3), 166-174. <https://doi.org/10.1177/1088357612472932>.
- Holy Bible, New International Version (1984) *New International Version Bible* online. <https://www.biblegateway.com/passage/?search=1+Corinthians+13&version=NI> V.
- Hope, A., & Timmel, S. (1984). *Training for transformation: A handbook for community workers*. Gweru: Mambo Press.
- Hope, A., & Timmel, S. (1986). *Training for transformation: A handbook for community workers*. Gweru: Mambo Press.
- Horkheimer, M. (1972). *Traditional and critical theory*. In M. T. O'Connell and others (Eds), *Critical theory* (pp. 188– 243). New York, NY: Herder and Herder.
- Horkheimer, M. (1995). *Critical theory: Selected essays*. New York: Continuum.
- Hornby, S. & Atkins, J. (1993). *Collaborative care interprofessional, interagency and interpersonal*. (2nd ed.). Oxford: Blackwell Scientific Publication.

- Houston, S., & Dolan, P. (2008). Conceptualising child and family support: The contribution of Honneth's critical theory of recognition. *Children and Society*, 22(6), 458–469. <https://doi.org/10.1111/j.1099-0860.2007.00126.x>.
- Humphrey, K. (2006). *How do social workers help the families of children with disabilities?* National Association of Social Workers. <http://www.helpstartshere.org/health-and-wellness/disabilities/how-do-social-workers-help-the-families-of-children-with-disabilities.html>.
- Imenda, S. (2014). Is there a conceptual difference between theoretical and conceptual frameworks? *Journal of Social Sciences*, 38(2), 185-195, DOI: 10.1080/09718923.2014.11893249.
- Jackson, J. B., Steward, S. R., Roper, S. O., & Muruthi, B. A. (2018). Support group value and design for parents of children with severe or profound intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders*, 48(12), 4207–4221. <https://doi.org/10.1007/s10803-018-3665-z>.
- James-Traore, T.A., Finger, W. Claudia, Ruland, D., & Savariaud, S. (2004) YouthNet. *Program Teacher Training: Essential for School-Based Reproductive Health and HIV/AIDS Education Focus on Sub-Saharan Africa*. Arlington, VA 22201, Family Health International.
- Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities*, 25(2), 98–109. <https://doi.org/10.1177/1088357610361344>.
- Kabzems, V., & Chimedza, R. (2002). Development assistance disability and education in Southern Africa. *Disability and Society*, 17, 147–157.
- Kalabula, M. D. (2000). *Inclusive education in Africa: A myth or reality? A Zambian case study*. Presentation at the International Special Education Congress, July 24-28. University of Manchester, UK.
- Kang-Yi, C. D., Grinker, R. R., Beidas, R., Agha, A., Russell, R., Shah, S. B., Shea, K., & Mandell, D. S. (2018). Influence of community-level cultural beliefs about autism on

- families' and professionals' care for children. *Transcultural Psychiatry*, 55(5), 623–647. <https://doi.org/10.1177/1363461518779831>.
- Kang, S. (2012). Coverage of autism spectrum disorder in the US television news : an analysis of framing. *Disability & Society*, 28(2), 245-259. <https://doi.org/10.1080/09687599.2012.705056>.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kapungwe, A., Cooper, S., Mwanza, J., Mwape, L., Sikwese, A., Kakuma, R., Lund, C., & Flisher, A. J. (2010). Mental illness - stigma and discrimination in Zambia. *African Journal of Psychiatry*, 192–203.
- Kapambwe S, Parham G, Mwanahamuntu M, Chirwa S, Mwanza J, Amuyunzu-Nyamongo M. Innovative approaches to promoting cervical health and raising cervical cancer awareness by use of existing cultural structures in resource-limited countries: experiences with traditional marriage counseling in Zambia. *Global Health Promotion*. 2013;20 (4_suppl):57-64. doi:[10.1177/1757975913502689](https://doi.org/10.1177/1757975913502689)
- Karisa, A., Mckenzie, J., & Villiers, T. De. (2020). To what extent is the schooling system willing to change to include disabled children ? *Disability & Society*, 35(9), 1520–1526. <https://doi.org/10.1080/09687599.2020.1809351>.
- Karisa, A., Mckenzie, J., & Villiers, T. De. (2021). ‘ *Their status will be affected by that child* ’: *How masculinity influences father involvement in the education of learners with intellectual disabilities*. *March*, 1–8. <https://doi.org/10.1111/cch.12864>.
- Karst, J. S., & van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15(3), 247–277. <https://doi.org/10.1007/s10567-012-0119-6>.
- Kelly, A., Ghalaieny, T., & Devitt, C. (2012). A pilot study of early intervention for families with children with or at risk of an intellectual disability in Northern Malawi. *Journal of Policy and Practice in Intellectual Disabilities*, 9(3), 195–205. <https://doi.org/10.1111/j.1741-1130.2012.00354.x>.
- Kemmis, S. , & McTaggart, R. (Eds.). (1988). *The action research planner* (3rd ed.). Geelong,

Victoria: Deakin University Press.

Kemmis, S., & McTaggart, R. (2007). Participatory action research: Communicative action and the public sphere. *Strategies of Qualitative Inquiry*, 271–330.

<https://doi.org/10.1080/09650790600975593>.

Kim, H. U. (2012). Autism across cultures : rethinking autism. *Disability & Society*, 27(4), 535–545. <https://doi.org/10.1080/09687599.2012.659463>.

Kincheloe, J. L., McLaren, P., & Steinberg, S. R. (2010). *Critical pedagogy and qualitative research*. The Sage handbook of qualitative research, pp. 163-177.

Kirk, S., & Glendinning, C. (2002). Supporting “expert” parents: Professional support and families

caring for a child with complex health care needs in the community. *International Journal of Nursing Studies*, 39(6), 625–635. [https://doi.org/10.1016/S0020-7489\(01\)00069-4](https://doi.org/10.1016/S0020-7489(01)00069-4).

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *International Journal of Jurisprudence and Philosophy of Law*, 1, 49–58. <https://doi.org/10.1111/j.1467-9337.2010.00473.x>.

Knapp, M., Romeo, R., & Beecham, J. (2009). The economic cost of autism in the UK. *Autism*, 13(3), 317–336. <https://doi.org/10.1177/1362361309104246>.

Kpobi L, Swartz L. (2019). Ghanaian traditional and faith healers' explanatory models of intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 32(1):43-50. doi: 10.1111/jar.12500.

Kramer-roy, D. (2009). *Exploring the support needs of Pakistani families with disabled children : A Participatory Action Research study*. Doctoral dissertation, Brunel University School of Health Sciences and Social Care.

Kramer-Roy, D. (2007). *Researching the support needs of Pakistani families with disabled children in the UK*. Unpublished thesis, Brunel University, Brunei.

Kramer-roy, D. (2015). Using participatory and creative methods to facilitate emancipatory research with people facing multiple disadvantages : A role for health and care professionals.

Disability & Society, 30 (8), 1207–1224.

<https://doi.org/10.1080/09687599.2015.1090955>.

Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E. and Christianson, A., 2008. Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 89-95.

Koch, T., Selim, P., & Kralik, D. (2002). Enhancing lives through the development of a community-based participatory action research program. *Journal of Clinical Nursing*, 11, 109-117.

Kozlowski, S. W. J., & Ilgen, D. (2006). Enhancing the effectiveness of work groups and teams: A reflection. *Psychological Science in the Public Interest.*, 77–124(3).
<https://doi.org/10.1177/1745691617697078>.

Kubota, T., & Mochizuki, K. (2016). Epigenetic effect of environmental factors on autism spectrum disorders. *International Journal of Environmental Research and Public Health*, 13(5), 1–12. <https://doi.org/10.3390/ijerph13050504>.

Kuo, M. H., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2014). Media use among adolescents with Autism Spectrum Disorder. *Autism*, 18, 914–923.
<https://doi.org/10.1177/1362361313497832>.

Kyndt, E., & Baert, H. (2013). Antecedents of employees' involvement in work-related learning: A systematic review. *Review of Educational Research.*, 83, 273–313.

Kyndt, E., & Baert, H. (2013). Antecedents of employees' involvement in work-related learning: A systematic review. *Review of Educational Research*, 83, 273–313.

Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gomez, V. A. (2012). The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Research and Practice for Persons with Severe Disabilities*, 37(1), 31–44.
<https://doi.org/10.2511/027494812800903247>.

Landa, R. . (2018). Efficacy of early interventions for infants and young children with, and at risk for, autism spectrum disorders. *International Review of Psychiatry*, 30(1), 25–39.
<https://doi.org/10.1080/09540261.2018.1432574>.

- Law, M., King, S., Stewart, D., & King, G. (2001). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 21(2/3), 30–48. https://doi.org/10.1080/J006v21n02_03.
- Leedy, P. D., & Ormrod, J. (2010). *Practical research, planning and design*. London: Pearson.
- Leonard, A. C. (1966). *The Lower Niger and its people*. London: Frank Cass.
- Levy, S. E., & Hyman, S. L. (2015). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, 24(1), 117–143. <https://doi.org/10.1016/j.chc.2014.09.004>.
- Lim, A. H., & Draper, E. (2011). The effects of music therapy incorporated with applied behaviour analysis verbal behaviour approach for children with autism spectrum disorders. *Journal of Music Therapy*, 48(4), 532–550. <https://doi.org/10.1093/jmt/48.4.532>.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. London: Sage.
- Lock, R. H., Hendricks, C. B., Bradley, L. J., & Layton, C. A. (2010). Using family leisure activities to support families living with autism spectrum disorders. *The Journal of Humanistic Counseling, Education and Development*, 49(2), 163–180. <https://doi.org/10.1002/j.2161-1939.2010.tb00095.x>.
- Lorenzo, T. (2005). *We don't see ourselves as different : A web of possibilities for disabled women : How black disabled women in poor communities equalise opportunities for human development and social change*. Unpublished thesis, University of Cape Town, Cape Town.
- Lotter, V. (1978). Childhood autism in Africa. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 19, 231– 244.
- Lotter, V. (1980). Cross-cultural perspectives on childhood autism. *Journal of Tropical Pediatrics*, 26, 131–133.
- Luther, E. H., Canham, D. L., & Cureton, V. Y. (2005). Coping and social support for parents of children with autism. 21(1). *The Journal of School of Nursing*.21(1)40-47.
- Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children

- diagnosed with an autism spectrum disorder. *Journal of Health Psychology*, 17(5), 702–711. <https://doi.org/10.1177/1359105311422955>.
- Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability and Society*, 26(6), 667–682. <https://doi.org/10.1080/09687599.2011.602860>.
- MacDonald, C. (2012). Understanding participatory action research: A qualitative research methodology option. *Canadian Journal of Action Research*, 13(2), 34–50. <http://ezproxy.lib.ucalgary.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ehh&AN=89233336&site=ehost-live>.
- Macha, V., Simui, F., & Muzata, K. (2020). Parents and teachers experiences of managing peculiar psychosocial behaviours of learners with an autism spectrum disorder in selected special units in Lusaka, Zambia. *Multidisciplinary Journal of Language and Social Sciences Education*, 3(2), 15–42.
- McDonald, J. (2013). Coming out in the field: A queer reflexive account of shifting researcher identity. *Management Learning*, 44(2), 127–143. <https://doi.org/10.1177/1350507612473711>. Retrieved from <http://doi.org/10.1177/1350507612473711>.
- Macnee, L. C., & McCabe, S. (2008). *Understanding nursing research: Using research evidence-based practice*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Magnussen, H. J. (2011). *Childhood disability in Rural Zambia: A qualitative study on the use of health care services*. Unpublished thesis, University of Oslo, Oslo.
- Mahmoudi, A. (2014). Paulo Freire critical pedagogy and its implications in curriculum planning. *Journal of Education and Practice*, 5(14), 86–93. <https://doi.org/10.1007/s10911-007-9040-x>.
- Makasa, E. (2009). The human resource crisis in the Zambian health sector : A discussion paper. *Medical Journal of Zambia*, 35(3). <https://doi.org/10.4314/mjz.v35i3.46522>
- Malungo, R. Nabuzoka, D., Paul, R., & Sachingongu, N. (2018). *Disability and education. A qualitative study from Zambia on barriers to and facilitators of life-long learning*. Lusaka: UNICEF.
- Mandell, D. S., & Novak, M. (2005). The role of culture in families’ treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental*

- Disabilities Research Reviews*, 11(2), 110–115. <https://doi.org/10.1002/mrdd.20061>
- Mandell, D. S., & Salzer, M. S. (2010). Who joins support groups among parents of children with autism? *Autism*, 11(2). <https://doi.org/10.1177/1362361307077506>.
- Maton, K. I. (2008). Empowering community settings: Agents of individual development, community betterment, and positive social change. *American Journal of Community Psychology*, 41(1–2), 4–21. <https://doi.org/10.1007/s10464-007-9148-6>.
- Matsumoto, D. (2006). Are cultural differences in emotional regulation mediated by personality traits? *Psychology, Journal of Cross-Cultural*, 37(4), 421–437. <https://doi.org/10.1177/0022022106288478>.
- Mayeya, J., Chazulwa, R., Mayeya, P. N., Mbewe, E., Magolo, L. . M., Kasisi, F., & Bowa, A. . C. (2004). Zambia mental health country profile. *International Review of Psychiatry*, 16(1–2), 63–72. <https://doi.org/10.1080/09540260310001635113>.
- Mazibuko, J. (2007). *Enhancing project sustainability beyond donor support. Analysis of grassroots democratisation as a possible alternative*. Unpublished dissertation, University of South Africa, Pretoria.
- Mazza, M., Pino, M. C., Vagnetti, R., Filocamo, A., Attanasio, M., Calvarese, A., & Valenti, M. (2020). Intensive intervention for adolescents with autism spectrum disorder: comparison of three rehabilitation treatments. *International Journal of Psychiatry in Clinical Practice*.1-9 <https://doi.org/10.1080/13651501.2020.1800042> .
- Merriam, S. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass
- Mbiti, J. S. (1969). *African Religions and Philosophy*. Gaborone: Heinemann.
- Mccabe, H. (2008). The importance of parent-to-parent support among families of children with autism in the people’s Republic of China. *International Journal of Disability, Development and Education*, 55(4), 303–314. <https://doi.org/10.1080/10349120802489471>.
- McConkey R, Samadi S.A.(2013). The impact of mutual support on Iranian parents of children with an autism spectrum disorder: A longitudinal study. *Disabil Rehabil.*;35(9):775-84.

doi: 10.3109/09638288.2012.707744.

- McConkey, R., Kelly, C., Craig, S., & Shevlin, M. (2015). A decade of change in mainstream education for children with intellectual disabilities in the Republic of Ireland. *European Journal of Special Needs Education*. 10.1080/08856257.2015.1087151.
- McGill, I., & Beaty, L. (1995). *A guide for professional, management and educational development* (2ed.). London: Stylus Publishing Inc.
- McIntosh, M. J., & Morse, J. M. (2015). Situating and constructing diversity in semi-structured interviews. *Global Qualitative Nursing Research*, 1–12.
<https://doi.org/10.1177/2333393615597674>.
- McKenzie, J., McConkey, R., & Adnams, C. (2013). Health conditions and support needs of persons living in residential facilities for adults with intellectual disability in Western Cape Province. *South African Medical Journal*, 103(7), 481–484.
<https://doi.org/10.7196/SAMJ.649>.
- McKenzie, J., McConkey, R., & Adnams, C. (2014). Caring for adults with intellectual disability in South Africa: Family members' perspectives. *Journal of Applied Research in Intellectual Disabilities*, 27(4), 354.
- McKenzie, J., & McConkey, R. (2016). Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 531–541.
- McNiff, J. (2002). *Action research: Principles and practice* (2nd ed.). London: Sage.
- McNiff, J., & Whitehead, J. (2006). *All you need to know about action research*. Thousand Oaks, CA: Sage.
- McNiff, J., & Whitehead, J. (2010). *You and your action research project* (3rd ed.). London: Routledge.
- McTaggart, R. (1994). Participatory action research issues in theory and practice. *Education Action Research*, 2(3), 313–337.
- Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability and*

- Society*, 26(6), 667–682. <https://doi.org/10.1080/09687599.2011.602860>.
- Mereoiu, M., Abercrombie, S., & Murray, M. (2016). One step closer : Connecting parents and teachers for improved student outcomes. *Cogent Education*, 30, 1–19. <https://doi.org/10.1080/2331186X.2016.1243079>.
- Mertens, D. M. (1999). Inclusive evaluation : Implications of transformative theory for evaluation. *American Journal of Evaluation*, 20(1), 1-14.
- Mertens, D. M., Bledsoe, K. L., Sullivan, M., & Wilson, A. (2010). Utilization of mixed methods for transformative purposes. In A. Tashakkori & C. Teddlie (Eds.), *Mixed methods in social & behavioral research* (p. 193-214). California: Thousand Oak.
- Sharan ,B & Merriam,S.A. (2009).*Qualitative Research: A Guide to Design and Implementation*. San Francisco: John Wiley & Sons
- Mia, H. (2009). Standing at Sinai With Autism. *Journal of Positive Behavior Interventions*, 11(3), 186–192.
- Miles, M., Huberman, M., & Saldana, J. (2020). *Qualitative data analysis: A methods sourcebook* (4th ed.). London: Sage.
- Minkowski, E., Targowla, R., & Ziadeh, S. (2001). A contribution to the study of autism: The interrogative attitude. *Philosophy, Psychiatry, & Psychology*, 8(4), 271–278. <https://doi.org/10.1353 ppp.2002.0020>.
- Molebatsi, K., Ndetei, D. M., & Opondo, P. R. (2017). Caregiver burden and correlates among caregivers of children and adolescents with psychiatric morbidity : A descriptive cross-sectional study. *Journal of Child & Adolescent Mental Health*, 29(2), 117-127. <https://doi.org/10.2989/17280583.2017.1340301>.
- Montgomery, L., Benzies, K., & Barnard, C. (2016). Effects of educator rounds. *Journal of Pediatric Nursing*, 31(2), e73–e82. <https://doi.org/10.1016/j.pedn.2015.10.008>.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counselling

- psychology. *Journal of Counselling Psychology*, 52(2), 250–260.
<https://doi.org/10.1037/0022-0167.52.2.250>.
- Mpofu, E., & Harley, D. A. (2002). Disability and rehabilitation in Zimbabwe: Lessons and implications for rehabilitation practice in the US. *Journal of Rehabilitation*, 68(4), 26–33.
- Mpolomoka, D. L. (2019). Bottom-up and top-down approaches to school management: Lessons from primary schools in Chadiza District, Eastern Province, Zambia. *Texila International Journal of Academic Research*, 6(2), 31–39.
<https://doi.org/10.21522/tijar.2014.06.02.art003>.
- Mthombeni, Z. C., & Nwoye, A. (2018). Black South African caregivers' understanding and responses to their children with autism spectrum disorder symptoms: A qualitative study. *South African Journal of Psychology*, 48(1), 99–111.
<https://doi.org/10.1177/0081246317696453>.
- Mulenga, D. (2019). An investigation into factors influencing enrolment of children with special education needs at Kapoche special school in Luangwa district of Lusaka Province, Zambia. *The International Journal of Multi-Disciplinary Research*, 1–36.
- Mulenga, E. M., & Marbán, J. M. (2020). Social media usage among pre-service secondary mathematics teachers in Zambia. *Journal of Research and Advances in Mathematics Education*, 5(2), 130–147. <https://doi.org/10.23917/jramathedu.v5i2.9920>.
- Mugumbate, J., & Nyanguru, A. (2013). Exploring African philosophy: The value of ubuntu in social work *African Journal of Social Work*, 3(1), 82–100.
- Müller, E., & Cannon, L. (2014). Parent perspectives on outcomes and satisfaction levels of young adults with Autism and cognitive impairments. *Focus on Autism and Other Developmental Disabilities*, 1–12. <https://doi.org/10.1177/1088357614528800>.
- Mulvany, J. (2000). Disability, impairment or illness: The relevance of social model of disabilities to the study of mental disorder. *Sociology of Health & Illness*, 22(5), 582–601.
- Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder:

- an interpretive phenomenological analysis. *Disability and Society*, 31(6), 798–819. <https://doi.org/10.1080/09687599.2016.1200015>.
- Murphy, C. M., & Verden, C. E. (2013). Supporting families of individuals with autism spectrum disorders: Developing a university-based respite care program. *Journal of Positive Behavior Interventions*, 15(1), 16–25. <https://doi.org/10.1177/1098300712436845>.
- Murray, M. M., Ackerman-spain, K., Williams, E. U., & Ryley, A. T. (2011). Knowledge is power : Empowering the autism community through parent-professional training. *School Community Journal*, 21(1), 19–36. <http://www.eric.ed.gov/PDFS/EJ932198.pdf>.
- Mwale, N., & Chita, J. C. (2016). Religious pluralism and disability in Zambia: Approaches and healing in selected pentecostal churches. *Studia Historiae Ecclesiasticae*, 42(2), 54–72.
- Mwape, L., Sikwese, A., Kapungwe, A., Mwanza, J., Flisher, A., Lund, C., & Cooper, S. (2010). Integrating mental health into primary health care in Zambia : A care provider’s perspective. *International Journal of Mental Health Systems*, 4(21), 1–9.
- Nachshen, J. S. (1997). Empowerment and families : Building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilities*, 11(1), 67-76.
- Neville, C., Beattie, E., Fielding, E., & Macandrew, M. (2015). Literature review: Use of respite by carers of people with dementia. *Health and Social Care in the Community*, 23(1), 51–63. <https://doi.org/10.1111/hsc.12095>.
- Ndhlovu, D., Serenje, J., Muzata, K., Mtonga, T., & Serenje-Chipindi, J. (2016). Early childhood education in Zambia: Inclusion of children with disabilities *International Journal of Multidisciplinary Research and Development*, 3(8), 126–132. <https://www.researchgate.net/publication/323831636>.
- Ndubani, P. and Höjer, B.1999. Traditional healers and the treatment of sexually transmitted illnesses in rural Zambia. *Journal of Ethnopharmacology*, 67(1), 15-25.
- Ngungu, J., & Beezhold, J. (2009). Mental health in Zambia: Challenges and way forward. *International Psychiatry*, 6(2), 39–40. <https://doi.org/10.1192/s1749367600000424>.

Nguyen, X. T. (2018). Critical disability studies at the edge of global development: Why do we

need to engage with southern theory? *Canadian Journal of Disability Studies*, 7(1), 1–25.
<https://doi.org/10.15353/cjds.v7i1.400>.

Nkhosi, J. K., & Menon, J. A. (2015). Mothers' perceptions on the needs of adolescent children with intellectual disabilities at George Clinic, Lusaka, Zambia. *Medical Journal of Zambia*, 42(4), 164–169. <https://doi.org/10.4314/mjz.v42i4>.

Nkole, L. (2017). *The prevalence and clinical characteristics of autism spectrum disorder in children aged 1-15 years seen at the University Teaching Hospital*. Unpublished thesis, University of Zambia, Lusaka.

Nsamenanga, B., & Tchombe, T.M. (2011). *Handbook of African Educational Theories and Practices: A generative teacher education Curriculum*. Bamenda: Presses Universitaires d' Afrique.

Nueman, W. (2012). *Basic of social research qualitative and quantitative approaches* (3rd ed.). London: Pearson.

Nyoni, J. (2011). *The Impact on parents of discovering that a child has Autism Spectrum Disorder: A phenomenological study of Lusaka parents*. Unpublished thesis, University of Zambia, Lusaka.

Nyoni, J., & Serpell, R. (2012). The impact on parents of raising a young child with autism: A phenomenological study of parents in Lusaka, Zambia. *International Journal of Disability, Community & Rehabilitation*, 11(1).
http://www.ijdcrc.ca/VOL11_01/articles/nyoni.shtml.

O'Dell, L., Rosqvist, H. B., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, 31(2), 166–179.

<https://doi.org/10.1080/09687599.2016.1164026>

O'Leary. (2017). *The essential guide to doing your research project*. London: Sage.

- Oino, P. G., Towett, G., Kirui, K. K., & Luvega, C. (2015). The dilemma in the sustainability of community-based projects in Kenya. *Global Journal of Advanced Research*, 4, 757–768.
- Oliver, M. (1990). *The politics of disablement: Critical texts in social work and the welfare state*. London: Macmillan Press Ltd.
- Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and Society*, 7(2), 101–114.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York: St. Martin's Press.
- Organisation of African Unity. (1999). *African Charter on the Rights and welfare of the child* (Vol. 49, Issue 1990).
- Osewska, E., Stala, J and Krzysztof, K. (2021). The Relationship between Religion and National Culture in Poland in Light of John Paul II's Philosophical and Theological Reflections. *Religions*.13: 33. <https://doi.org/10.3390/rel13010033>.
- Oti-Boadi, M., Dankyi, E., & Kwakye-Nuako, C. O. (2020). Stigma and forgiveness in Ghanaian mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 50, 1391–1400. <https://doi.org/10.1007/s10803-020-04366-x>.
- Pandey, V., Mukherjee, S. K., & Jha, A. (2021). Literature review of online patient groups : Benefits and limitations. *Linguistica Antverpiensia*, 2, 197–218.
- Pandya, S. P. (2018). Spirituality to build resilience in primary caregiver parents of children with autism spectrum disorders: A cross-country experiment. *International Journal of Develop- Mental Disabilities*, 64, 53–64. <https://doi.org/10.1080/20473869.2016.1222722>.
- Parnes, P., Cameron, C., Chiiya, C., Hashemi, G., & Njelesani, J. (2015). *Prospects and Challenges of Inclusive Education in Zambia: 2015 Study Report*. Lusaka: Ministry of Education.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods (3rd ed.)*. Thousand Oaks,

CA: Sage.

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). London: Sage.

Pepperell, T. A., Paynter, J., & Gilmore, L. (2018). Social support and coping strategies of parents raising a child with an autism spectrum disorder. *Early Child Development and Care*, 188(10), 1392–1404. <https://doi.org/10.1080/03004430.2016.1261338>.

Pinkerton, J., & Dolan, P. (2007). Family support, social capital, resilience, and adolescent coping. *Child & Family Social Work.*, 12, 12, 219–228.

Pitten, K. (2008). How cultural values influence diagnosis, treatment and the welfare of families with an autistic child. *InSight: Rivier Academic Journal*, 4(1), 1–5.

Predescu, M., & Darjan, I. (2018). An ecological approach of Autism Spectrum Disorders An ecological approach of Autism Spectrum Disorders. *Journal of Educational Sciences*, 19, 31-43 <https://doi.org/10.35923/JES.2018.2.03>.

Pruitt, M. M., Willis, K., Timmons, L., & Ekas, N. V. (2016). The impact of maternal, child, and family characteristics on the daily well-being and parenting experiences of mothers of children with an autism spectrum disorder. *Autism*, 20(8), 973-985. <https://doi.org/10.1177/1362361315620409>.

Radermacher, H. (2006). *Participatory action research with people with disabilities: Exploring participation*. Unpublished thesis, University of Victoria.
<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.667.3610&rep=rep1&type=pdf>.

Ramseur II, K., De Vries, P., Guler, J., Shabalala, N., Seris, N., & Franz, L. (2019). Caregiver descriptions of joint activity routines with young children with an autism spectrum disorder in South Africa. *Pediatric Medicine*, 2(6), 1–11. <https://doi.org/10.21037/pm.2019.03.04>.

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability : A review and focus on Autism. *Journal of Child and Family Studies*, 21, 311–319. <https://doi.org/10.1007/s10826-011-9477-9>.

Ravindran, N., & Myers, B. J. (2013). Beliefs and practices regarding autism in Indian families

now settled abroad: An internet survey. *Focus on Autism and other Developmental Disabilities*, 28(1), 44–53. <https://doi.org/10.1177/1088357612458970>

Reason, P., & Bradbury, H. (2008). *Action research*. London: Sage.

Reichow B, Servili C, Yasamy MT, Barbui C, Saxena S (2013) Non-Specialist Psychosocial Interventions for Children and Adolescents with Intellectual Disability or Lower-Functioning Autism Spectrum Disorders: A Systematic Review. *PLoS Med* 10(12): e1001572. doi:10.1371/journal.pmed.100157.

Retief, M., & Letsosa, R. (2018). Models of disability: A brief overview. *HTS Teologiese Studies/ Theological Studies*, 74(1), 1–8. <https://doi.org/10.4102/htsv74i4738>.

Richie, C. (2015). Do not hinder them: Educating children with mental disabilities in the church. *International Journal of Children's Spirituality*, 20(2), 72–85. <https://doi.org/10.1080/1364436X.2015.1030593>.

Rockers, P. C., Fink, G., Zanolini, A., Banda, B., Biemba, G., Sullivan, C., Mutembo, S., Silavwe, V., & Hamer, D. H. (2016). Impact of a community-based package of interventions on child development in Zambia: A cluster-randomised controlled trial. *BMJ Global Health*, 1(3), e000104. <https://doi.org/10.1136/bmjgh-2016-000104>.

Rockers, P. C., Zanolini, A., Banda, B., Chipili, M. M., Hughes, R. C., Hamer, D. H., & Fink, G. (2018). Two-year impact of community-based health screening and parenting groups on child development in Zambia: Follow-up to a cluster-randomised controlled trial. *PLoS Medicine*, 15(4), 1–15. <https://doi.org/10.1371/journal.pmed.1002555>.

Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review*, 5, 243–258.

Rossman, G. B., & Marshall, C. (2011). *Designing qualitative research*. (5th ed.). London: Sage.

Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. London: Sage.

Ruble, L. A., & Dalrymple, N. J. (2002). Compass: A parent-teacher collaborative model for students with autism. *Focus on Autism and Other Developmental Disabilities*, 17(2), 76–

83. <https://doi.org/10.1177/10883576020170020201>.

Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M. ., Visser, K., Chugani, D. ., Donal, K. ., Wilmschurst, J. ., Shih, A., Skuse, D., & Newton, C. (2016). Autism spectrum disorders in Africa : Current challenges in identification, assessment, and treatment : A report on the international child neurology association meeting on. *Journal of Child Neurology*, August, 1–9. <https://doi.org/10.1177/0883073816635748>.

Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, 17(2), 95–104. <https://doi.org/10.1177/1098300714532134>.

Samadi, S. A., & McConkey, R. (2011). Autism in developing countries: Lessons from Iran. *Autism Research and Treatment*. <https://doi.org/10.1155/2011/145359>.

Samadi, S. A., McConkey, R., & Kelly, G. (2012). The information and support needs of Iranian parents of children with autism spectrum disorders. *Early Child Development and Care*, 182(11), 1439–1453. <https://doi.org/10.1080/03004430.2011.616931>.

Samadi, S. A., McConkey, R., & Kelly, G. (2013). Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorder. *Autism : The International Journal of Research and Practice*, 17(1), 27–43. <https://doi.org/10.1177/1362361311435156>.

Samadi, S. A., Samadi, H., & McConkey, R. (2015). A conceptual model for empowering families in less affluent countries who have a child with autism. *Autism Spectrum Disorder - Recent Advances*. <https://doi.org/10.5772/59111>.

Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: Case studies in South Africa. *International Nursing Review*, 60, 344–350. <https://doi.org/10.1111/inr.12022>.

Schlebusch, L., Samuels, A. E., & Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal and family quality of life. *Journal of Intellectual Disability Research*, 60 (5), 412–423. <https://doi.org/10.1111/jir.12292>.

- Schofield, T. J., Conger, R. D., Donnellan, M. B., Jochem, R., & Conger, K. J. (2013). Parent personality and positive parenting as predictors of positive adolescent personality development over time. *Merrill-Palmer Quarterly*, 58 (2), 1–22. <https://doi.org/10.1353/mpq.2012.0008>.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life-course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106(3), 265–286. [https://doi.org/10.1352/0895-8017\(2001\)106<0265:LCIOPA>2.0.CO;2](https://doi.org/10.1352/0895-8017(2001)106<0265:LCIOPA>2.0.CO;2).
- Serpell, R. (1980). Linguistic flexibility in urban Zambian children. *Annals of the New York Academy of Sciences*, 345, 97-119.
- Serpell, R., & Jere-Folotiya, J. (2008). Developmental assessment, cultural context, gender, and schooling in Zambia. *International Journal of Psychology*, 43(2), 88–96. <https://doi.org/10.1080/00207590701859184>.
- Serpell, R., & Jere-Folotiya, J. (2011). Basic education for children with special needs in Zambia: Progress and challenges in the translation of policy into practice. *Psychology & Developing Societies*, 23(2), 211–245. <https://doi.org/10.1177/097133361102300204>.
- Sefotho, M. M. (2021). Basotho ontology of disability: An Afrocentric onto-epistemology. *Heliyon*, 7(3), e06540. <https://doi.org/10.1016/j.heliyon.2021.e06540>.
- Sen, A. (1979) *Equality of What?* Amartya Sen the Tanner Lecture on Human Values. Delivered at Stanford University May 22, 1979
- Sen, A. K. (1985). "Well-Being, Agency and Freedom: The Dewey Lectures 1984," *The Journal of Philosophy*, 82, 169-221.
- Sen, A. (1993). Capability and well-being. In Martha Nussbaum & Amartya Sen (Eds.), *Quality of Life* (pp. 30-53). Oxford: Clarendon Press.
- Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*, 6(1), 8–21. <https://doi.org/10.1080/15017410409512636>.
- Shen, G. C., Nguyen, H. T. H., Das, A., Sachingongu, N., Chansa, C., Qamruddin, J., & Friedman, J. (2017). Incentives to change: Effects of performance-based financing on health workers in Zambia. *Human Resources for Health*, 15(1), 20. <https://doi.org/10.1186/s12960-017-0179-2>.

- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-75. doi:10.3233/EFI-2004-22201.
- Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with an autism spectrum disorder. *Anxiety, Stress and Coping*, 31(3), 277–290. <https://doi.org/10.1080/10615806.2018.1442614>.
- Sheratt, Y. (2010). Adorno and Horkheimer's concept of 'enlightenment. *British Journal for the History of Philosophy*, 6(3) 521-544. doi:1080/096087800442165.
- Shultz, A. J., Israel, B. A., Zimmerman, M. A., & Checkoway, B. N. (1995). Empowerment as a multi-level construct: Perceived control at the individual, organisational, and community levels. *Health Education Research: Theory and Practice*, 10, 309–327.
- Sibanda, P. (2016). *Impact of the Free Primary Education Policy on the Education of Learners with Disabilities : A survey of Inclusive and Special Schools in Lusaka District of Zambia*. Unpublished thesis, University of Zambia, Lusaka.
- Sibani.C.M.(2018). Impact of Western culture on traditional Afrian society: problems and prospects. *Journal of religion and Human Relations*,10,56-72.
- Singogo, C., Mweshi, M., & Rhoda, A. (2014). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, 71(1), 1–6. <https://doi.org/10.4102/sajp.v71i1.274>.
- Skinner, D., Bailey, D. B., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers' construction of identities vis a grave; vis their child with special needs. *Exceptional Children*, 65(4), 481–495.
- Smith, L. E., & Anderson, K. a. (2013). The roles and needs of families of adolescents with ASD. *Remedial and Special Education*, 35(2), 114–122. <https://doi.org/10.1177/0741932513514616>.
- Smith, L., Malcolm-Smith, S., & De Vries, P. (2016). Translation and cultural appropriateness of the Autism Diagnostic Observation Schedule-2 in Afrikaans. *Autism, Special Issue Article*, 1–12. <https://doi.org/10.1177/1362361316648469>.
- Snelson, P. (1974). *Education development in Northern Rhodesia 1883-1945*. Lusaka:

Kenneth Kaunda Foundation.

- Sollazzo, F. (2016). The Marcusean inheritance is a possibility not yet realised: From a pre-to a post-technological culture and society. *Revista Polis*, 4 (14), 25–49.[http://revistapolis.ro/documente/revista/2016/Numarul_4\(14\)2016/editorial/3_F_Sollazzo.pdf](http://revistapolis.ro/documente/revista/2016/Numarul_4(14)2016/editorial/3_F_Sollazzo.pdf).
- Spalding, E., & Wilson, A. (2002). Demystifying reflection : A study of pedagogical strategies that encourage reflective journal writing. *Teachers College Record*, 104(7), 1393-1421.
- Stahmer, A. C., Brookman-Frazee, L., Rieth, S. R., Stoner, J. T., Feder, J. D., Searcy, K., & Wang, T. (2016). Parent perceptions of an adapted evidence-based practice for toddlers with autism in a community setting. *Autism* 21(2), 217-230. <https://doi.org/10.1177/1362361316637580>.
- Steinberg, S. R., & Kincheloe, J. L. (2010). Power, emancipation, and complexity: Employing critical theory. *Power & Education*, 2(2), 140–151. <https://doi.org/10.2304/power.2010.2.2.140>.
- Stekelenburg, J., Jager, B., Kolk, P., Westen, E., van der Kwaak, A., & Wolffers, I. (2005). Health care-seeking behaviour and utilisation of traditional healers in Kalabo, Zambia. *Health Policy*, 71(1), 67–81. <https://doi.org/healthpol.2004.05.008>.
- Stringer, E. T. (2014). *Action research*. London: Sage.
- Stephens, J (2018). Meeting the needs of children with autism and their parents during out-of-hospital interactions with paramedics. Unpublished thesis, Queensland University of Technology.
- Swartz, S., & Nyamnjoh, A. (2018). Research as freedom: Using a continuum of interactive, participatory and emancipatory methods for addressing youth marginality. *HTS Teologiese Studies / Theological Studies*, 74(3), 11 pages. doi:<https://doi.org/10.4102/hts.v74i3.5063>.
- Suarez-Balcazar, Y., Balcazar, F., Garcia-Ramirez, M., & Taylor-Ritzler, T. (2014). Ecological theory and research in multicultural psychology: A community psychology perspective. In F. L. Leong, L. Comas-Díaz, G. C. Nagayama Hall, V. C. McLoyd, J. E. Trimble, F.

- L. Leong, ... J. E. Trimble (Eds.). In *APA handbook of multicultural psychology, Vol. 1: Theory and research*. American Psychological Association Inc. <https://doi.org/10.1037/14189-029>.
- Sue, D. W., & Sue, D. (2003). Sociopolitical considerations of trust and mistrust in multicultural counselling and therapy. In *Counseling the culturally different: Theory and practice* (3rd ed.), pp. 63-90). New York: John Wiley and Sons. Check that all edietd book items like this one are formatted consistently.
- Sugishita, K. (2009). Traditional medicine, biomedicine and Christianity in modern Zambia. *Africa*, 79(3), 435–454. <https://doi.org/10.3366/E0001972009000904>.
- Sutton, J. and Austin, Z. (2015). Qualitative Research: Data Collection, Analysis, and Management. *The Canadian Journal of Hospital Pharmacy*, 68, 226-231. <https://doi.org/10.4212/cjhp.v68i3.1456>
- Tekinarslan, İ. Ç. (2018). Autism Spectrum Disorder: Experiences of Mothers Before and After Their Children's Diagnosis and Implications for Early Special Education Services. *Journal of Education and Training Studies*, 6(12), 68. <https://doi.org/10.11114/jets.v6i12.3692> Take out incorrect capital letters.
- Tarakeshwar, N., & Pargament, K. I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities*, 16(4), 247–260.
- Tehee, E., Hevey, D., Tehee, E., Honan, R., & Hevey, D. (2008). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22(April), 34–42. <https://doi.org/10.1111/j.1468-3148.2008.00437.x>.
- Tekola, B., Kinf, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social science & medicine (1982)*, 256, 113034. <https://doi.org/10.1016/j.socscimed.2020.113034>.
- Tekinarslan, İ. Ç. (2018). Autism Spectrum Disorder: Experiences of Mothers Before and After Their Children's Diagnosis and Implications for Early Special Education Services. *Journal of Education and Training Studies*, 6(12), 68.

<https://doi.org/10.11114/jets.v6i12.3692>

The Government of the Republic of Zambia. (1996a). *Educating our future*. Lusaka: Ministry of Education.

The Government of the Republic of Zambia. (1996b). *The Constitution of Zambia*. Lusaka.

The Government of the Republic of Zambia. (2010). *2010 Census of Population and Housing*. Lusaka: Central Statistics.

The Government of the Republic of Zambia. (2011). *National Health Strategic Plan 2011-2015*. <http://www.moh.gov.zm/docs/nhsp.pdf>

The Government of the Republic of Zambia. (2012a). *Census of Population and Housing 2010: National Analytic Report*. Lusaka: Central Statistics.

The Government of the Republic of Zambia. (2012b). *Zambia National Health Policy: A Nation of Healthy and Productive People*". <https://doi.org/10.1136/bmj.2.4312.279>

The Government of the Republic of Zambia. (2013). *The Persons with Disabilities Act of 2012*. Lusaka.

The Government of the Republic of Zambia. (2017a). *Education Statistical Bulletin 2016*. Ministry of General Education, Lusaka.

The Government of the Republic of Zambia. (2017b). *Zambia National Health Strategic Plan 2017 – 2021*. <https://www.medbox.org/countries/zambia-national-health-strategic-plan-2017-2021/preview%0Ahttp://www.moh.gov.zm/docs/ZambiaNHSP.pdf>

The Government of the Republic of Zambia. (2018). *Zambia National Disability Survey 2015*. Lusaka: Central Statistics Office.

The Government of the Republic of Zambia. (2018). *BHC for UHC project: Study on the unit costs of health services provided at hospitals and health centres in Lusaka and Southern provinces, Zambia*

The Government of the Republic of Zambia. (2019). *Mental Health Act 2019*. Lusaka: The Government of the Republic of Zambia.

The Government of the Republic of Zambia. (2020). *Financing framework: Home-grown*

school meals programme in Zambia. Lusaka: Ministry of General Education.

The Government of the Republic of Zambia. (2021). *Estimates of Revenue and Expenditure. (Output Based Budget) For the Year 1 st January 2021 to 31st December 2021*. Lusaka: The Government of the Republic of Zambia.

The World Bank. (2015). *Mapping subnational poverty in Zambia*
<http://documents.worldbank.org/curated/en/766931468137977527/Mapping-subnational-poverty-in-Zambia>

Thomas, E., & Magilvy, J. K. (2011). *Qualitative rigour or research validity in qualitative research*. 151–155. <https://doi.org/10.1111/j.1744-6155.2011.00283.x>.

Thompson, J. D. (2019). Children with autism and congregations: Leader's assessments of knowledge, programming, and potentialities. *Social Work & Christianity*, 46(4), 24. <https://doi.org/org/10.34043/swc.v46i4.102>.

Tint, A., & Weiss, J. A. (2015). Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism : The International Journal of Research and Practice*, 1362361315580442. <https://doi.org/10.1177/1362361315580442>.

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., Saxena, S., Kennedy, J. P., & Foundation, J. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research*, 58(12), 1121–1130. <https://doi.org/10.1111/jir.12106>.

Tripathi, N. (2015). Parenting style and parents' level of stress having children with autistic spectrum disorder (CWASD): A study based on Northern India. *Journal of Neuropsychiatry*, 1(1), 1–8. <https://doi.org/10.21767/NPY.1000107>.

Trivette, C. M., & Dunst, C. J. (2014). Community-based parent support programmes. In *Encyclopedia of early childhood development*, pp. 1–6. Orellana Hawks Puckett Institute.

Tshabalala, N. (2014). *An Exploration of parents' experiences of the inclusion and retention of their disabled children in public schools in Eastern Cape Province*. Unpublished thesis, University of Cape Town, Cape Town.

Tudge, J. R. H., Mokrova, I. L., Hatfield, B. E., & Karnik, R. B. (2009). Uses and misuses of

- Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory and Review*, 1, 198–210.
- Turnbull, A. P., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust*. London: Pearson.
- Turner-Brown, L., Hume, K., Boyd, B. A., & Kainz, K. (2019). Preliminary efficacy of family implemented TEACCH for toddlers: Effects on parents and their toddlers with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49(7), 2685–2698. <https://doi.org/10.1007/s10803-016-2812-7>.
- Ulofoshio, J. I. (2017). *Lived experiences of mothers raising children with an autism spectrum disorder in Nigeria*. Unpublished doctoral dissertation, Walden University.
- Union Against Physically Impaired Segregation. Fundamental Principles of Disability (1975). London: UPIAS. Viewed 23 February 2018 from <http://www.disability.co.uk/fundamentalprinciples-disability>.
- United Nations. Department of Economic and Social Affairs. (2012). *United Nations Department of Economic and Social Affairs* (Issues 15-17 May 2012).
- United Nations. (2015). *Getting started with the sustainable development goals*. Convention on the Rights of Persons with Disabilities, Pub. L. No. CRPD/c/GC/4, 20881 CRPD/C/GC/4 1 (2016). <https://doi.org/10.4135/9781483346663.n124>.
- United Nations Children's Fund. (2006). *The State of World Children.Excluded and Invisible*.New York: Unicef.
- United Nations Children's Fund. (2006). Promoting the rights of children with disabilities. In *Unicef Office of Research* (Issue 13). <http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>.
- United Nations General Assembly. (2006). *Convention on the rights of persons with disabilities*. Retrieved on 23/11/2019 from <https://www.un.org/disabilities/documents/convention/convoptprote.pdf>.
- United Nations General Assembly. (2007). *Resolution adopted by the General Assembly on 18 December 2007. 62/139. World Autism Awareness Day*.New York:UN

- United Nations General Assembly. (2017). *Report of the Special Rapporteur on the rights of persons with disabilities on her visit to Zambia: Vol. A/HRC/34/5* (Issue 19 December 2016). Convention on the rights of persons with disabilities, 2515 3 (2006). <http://www.un.org/disabilities/Convention on the Rights of Persons with Disabilities and Optional Protocol>, (2006).
- Van der Mark, E. J. (2019). *Against all odds: Exploring wellbeing transformation with mothers of disabled children from poor urban settlements in Southern Africa*. Unpublished thesis, University of Vrije Universiteit Amsterdam, Amsterdam.
- Virolainen, S., Hussien, W., & Dalibalta, S. (2020). Autism spectrum disorder in the United Arab Emirates: potential environmental links. *Reviews on Environmental Health*, 35(4), 359–369. <https://doi.org/https://doi.org/10.1515/reveh-2020-0025>.
- Vivanti, G., Paynter, J., Durcan, E., Fothergill, H., Dissanayake, C., & Rodgers, S.(2014). Effectiveness and feasibility of the early start Denver model implemented in a group-based community childcare setting. *Journal of Autism and Developmental Disorders*, 44(12), 3140–3153. <https://doi.org/10.1007/s10803-014-2168-9>.
- Vollman, A. R., Anderson, E. T., & McFarlane, J. (2004). *Canadian Community as a partner*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Walliman, N. (2011). *Your research project: Designing and planning your work* (3rd ed.). London: Sage.
- Wang, P., & Michaels, C. A. (2010). Chinese families of children with severe disabilities : Family needs and available support. *Research and Practice for Persons with Disabilities*, 34(2), 21–32.
- Wannenburg, N., & van Niekerk, R. (2018). Early diagnosis and intervention for autism spectrum disorder in Africa: Insights from a case study. *African Health Sciences*, 18(1), 137–146. <https://doi.org/10.4314/ahs.v18i1.18>.
- Ward, K., & Trigler, J. S. (2001). Reflections on participatory action research with people who have developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 39, 57–59.

- Washington-Nortey, P., & Serpell, Z. (2021). Research in developmental disabilities parental expectations for children with intellectual disability or autism in Ghana and Zambia : A concept mapping study. *Research in Developmental Disabilities*, 114 (August 2020), 1–10. <https://doi.org/10.1016/j.ridd.2021.103989>.
- Watermeyer, B. (2013). *Towards a Contextual Psychology of Disablism*. London: Routledge.
- Wei, Y. S., Chu, H., Chen, C. H., Hsueh, Y. J., Chang, Y. S., Chang, L. I., & Chou, K. R. (2012). Support groups for caregivers of intellectually disabled family members: Effects on physical-psychological health and social support. *Journal of Clinical Nursing*, 21(11–12), 1666–1677. <https://doi.org/10.1111/j.1365-2702.2011.04006.x>.
- Weisner, T. S., Beizer, L., & Stolze, L. (1991). Religion and families of children with developmental delays. *American Journal on Mental Retardation*, 95(6), 647–662.
- Weiss, A.J., Wingsiong, A. and L. (2014). *Defining crisis in families of individuals with autism Spectrum Disorders Autism*. 8, 985–995. <https://doi.org/10.1177/1362361313508024> PMID: PMC4230960.
- Wonani, L., & Muzata, K. . (2019). Parenting and educating children with autism : Lived experiences of Lusaka parents - Zambia. *International Journal of Sciences: Basic and Applied Research*, 20-36.
- Woods, R. (2017). Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt. *Disability & Society*. 32 (7), pp. 1090-1095. <https://doi.org/10.1080/09687599.2017.1328157>.
- Woolley, T., Sivamalai, S., Ross, S., Duffy, G., & Miller, A. (2013). Indigenous perspectives on the desired attributes of medical graduates practising in remote communities : A Northwest Queensland pilot study. *Australian Journal of Rural Health*, 21(2), 90–96. <https://doi.org/10.1111/ajr.12018>.
- World Health Organisation. (2007). *International classification of functioning, disability and health for children and youth and is known as the ICF-CY*. Geneva: WHO.
- World Health Organisation (2010). CBR Guidelines: Empowerment Component. *WHO Library Cataloguing-in-Publication Data*.

http://apps.who.int/iris/bitstream/10665/44405/5/9789241548052_empower_eng.pdf

World Health Organisation (2011). *World Report on Disability*. Geneva: World Health Organization.

World Health Organisation (2013b). *Autism spectrum disorders & other developmental disorders From raising awareness to building capacity*. Geneva: World Health Organization.

World Health Organization. (2013a). *WHO Traditional Medicine Strategy: 2014-2023*. Geneva: World Health Organization.

World Medical Association .(2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA*, 310(20), 2191-2194. doi: 10.1001/jama.2013.281053. PMID: 24141714.

World Health Organisation. (2019). *Peer support groups by and for people with lived experience: WHO QualityRights guidance module*. Geneva: WHO.

World Health Organisation .(2020). Sustainable development goals: Guidelines for the use of the SDG Logo. In *United Nations Department of Global Communications*.
<https://www.un.org/sustainabledevelopment/news/communications-material>.

Yin, R. K. (2016). *Qualitative research from the start to finish*. New York: Guilford Press.

Yu, L., Stronach, S., & Harrison, A. J. (2020). Public knowledge and stigma of autism spectrum disorder: Comparing China with the United States. *Autism*, 24(6), 1531–1545.
<https://doi.org/10.1177/1362361319900839>.

Yusuf, A., & Elsabbagh, M. (2015). At the crossroads of participatory research and biomarker discovery in autism: The need for empirical data. *BMC Medical Ethics*, 16(1), 88.
<https://doi.org/10.1186/s12910-015-0082-0>.

Zambia Mental Health Users Network. (2014). *Human rights and mental health in Zambia* (Mental health). http://www.mdac.org/sites/mdac.info/files/zambia_layout_web4.pdf.

Zeglam, A. M., & Maouna, A. (2012). Is there a need for a focused health care service for children with autistic spectrum disorders? A keyhole looks at this problem in Tripoli,

- Libya. *Autism*, 16(4), 337–339. <https://doi.org/10.1177/1362361310393535>.
- Zhang, J. (2010). A review of Autism Spectrum Disorders from a perspective of Classical Chinese Medicine. *Journal of Traditional Chinese Medicine*, 30(1), 53–59. [https://doi.org/10.1016/s0254-6272\(10\)60014-3](https://doi.org/10.1016/s0254-6272(10)60014-3).
- Zhao, Y., Zhang, J., & Wu, M. (2019). Finding users' voice on social media: An investigation of online support groups for autism-affected users on Facebook. *International Journal of Environmental Research and Public Health*, 16(23). <https://doi.org/10.3390/ijerph16234804>.
- Zimba.M (2014, May 14,) *Chimbuya: Helping to hold Zambia together*.Times of Zambia<https://www.times.co.zm/?p=22291>: retrived12/01/2021 from <http://www.times.co.zm/?p=22291>.

APPENDICES

Appendix A: Ethics Clearance Letter from the University of Cape Town



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

22 August 2017

HREC REF: 113/2017

Dr Judith McKenzie
Health & Rehab
F-floor, OMB

Dear Dr McKenzie

PROJECT TITLE: A PARTICIPATORY ACTION RESEARCH PROJECT ON FAMILY NEEDS AND AVAILABLE SUPPORT SERVICES FOR ZAMBIAN FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS (PhD-candidate-J Nyoni)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 August 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

The HREC acknowledge that the student, Joachim Nyoni will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

HREC 113/2017

Appendix B: Ethics Clearance from Ministry of Health Agency-ERES



33 Joseph Mwilwa Road
Rhodes Park, Lusaka
Tel: +260 955 155 633
+260 955 155 634
Cell: +260 966 765 503
Email: eresconverge@yahoo.co.uk

I.R.B. No. 00005948
F.W.A. No. 00011697

27th November, 2017

Ref. No. 2017-Oct-023

The Principal Investigator
Mr. Joachim Nyoni
Ministry of General Education
Early Childhood Directorate
P.O. Box 50093,
LUSAKA.

Dear Mr. Nyoni,

**RE: A PARTICIPATORY ACTION RESEARCH PROJECT ON FAMILY NEEDS
AND AVAILABLE SUPPORT SERVICES FOR ZAMBIAN FAMILIES OF
CHILDREN WITH AUTISM SPECTRUM DISORDERS**

Reference is made to your corrections and meeting. The IRB resolved to approve this study and your participation as Principal Investigator for a period of one year.

Review Type	Ordinary	Approval No. 2017-Oct-023
Approval and Expiry Date	Approval Date: 27 th November, 2017	Expiry Date: 26 th November, 2018
Protocol Version and Date	Version – Nil	26 th November, 2018
Information Sheet, Consent Forms and Dates	• English.	26 th November, 2018
Consent form ID and Date	Version - Nil	26 th November, 2018
Recruitment Materials	Nil	26 th November, 2018
Other Study Documents Questionnaires,	Interview Schedules/ Guides.	26 th November, 2018
Number of participants approved for study	55	26 th November, 2018

Where Research Ethics and Science Converge

Appendix C: Authorisation Letter from the National Health Research Authority



THE NATIONAL HEALTH RESEARCH AUTHORITY
Paediatrics Centre of Excellence
University Teaching Hospital
P.O Box 30075
LUSAKA

11th January, 2018

Mr. Joachim Nyoni
Ministry of General Education
Early Childhood Directorate
P.O Box 50093
LUSAKA

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"A Participatory Action Research Project on Family Needs and Available Support Services for Zambian Families of Children with Autism Spectrum Disorders"**.

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been approved to carry out the above mentioned exercise on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

Dr. Godfrey Biemba
CEO/Director
National Health Research Authority

Appendix D: Authorisation Letter to use the Assessment Centre for Data Collection Ministry of General Education

Directorate of Early Childhood Education

P.O. Box 500093

Lusaka

Email: joachimnyoni@gmail.com

Cell: +260977318702/ +260967318702

The principal

Zambia Institute of Special Education

P.O Box 320081

Lusaka

Dear Sir/Madam,

REF: Research recruitment of families of children with Autism Spectrum Disorder.

Please, refer to the subject matter above. I am a registered PhD student at the University of Cape Town, doing a research study titled, A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services Available among Zambian Parents of Children with Autism Spectrum Disorders. HREC number (113/2017).

I write for your assistance in recruiting families of children with ASD from your database. These parents could be biological parents or caregivers who have a child aged between 3-12 years old, was diagnosed with ASD and were certified by qualified health professionals.

The information to be obtained will be purely for academic purposes. I will appreciate it that you contact them on my behalf and inform them about the study and its objectives and their willingness to be part of the research project.

The purpose of this study is to identify the family support needs of children with ASD and find out what additional services they need. Furthermore, I want to find out how families and professionals experience current services and what additional support they would require in future.

The findings from this study will be of great value to many institutions that provide services to children with ASD. It will assist in having a greater in-depth understanding of the unmet needs of families of children with ASD. Furthermore, your institution stands to benefit as it trains special education teachers who work with families and children with various disabilities, ASD included.

Kindly find attached the ethics approved letters from the University of Cape Town and Zambia Ministry of Health Ethics Board Committee which has cleared me to proceed with the study.

Thanking you in advance and looking forward to your reply.

Yours faithfully,

Nyoni Joachim (Student)

University of Cape Town

Faculty of Health Sciences

Department of Health and Rehabilitation

Cell: 260977318702 email: nynjoa002@myuct.ac.za

Dr Judith McKenzie (Supervisor)

University of Cape Town

Faculty of Health Sciences

Department of Health and Rehabilitation

Phone: 0214066318 Cell: 0835000464, e-mail: Judith.mckenzie@uct.ac.za

Appendix E: Authorisation Letter to Use ZAMISE Assessment Centre

All correspondence should be addressed to:
The Principal

In reply please quote:
No:.....



Telephone: +260 211 232408/232407



REPUBLIC OF ZAMBIA
MINISTRY OF GENERAL EDUCATION

ZAMBIA INSTITUTE OF SPECIAL EDUCATION
EDUCATION BOARD
P.O. BOX 320081
WOODLANDS
LUSAKA.

3rd January, 2018

Mr. Nyoni
Ministry of General Education
LUSAKA

RE: USE OF ZAMISE ASSESSMENT CENTRE

Kindly be informed that permission has been granted for you to use the Assessment Centre for your research. Just remember to maintain confidentiality and observe ethics for the sake of our clients.

Wish you success in your research.

G.M. Kachenga

G.M. Kachenga. (Mrs)
Principal
Zambia Institute of Special Education

*bmn....

Appendix F: Authorisation Letter from the Provincial Education Officer

*All communications should be addressed to
the Provincial Educational Officer and not
to any individual by name*

Telephone: +260 - 211 - 250655 / 251220
Fax: +260 - 251009



REPUBLIC OF ZAMBIA

MINISTRY OF GENERAL EDUCATION

OFFICE OF THE PROVINCIAL EDUCATION OFFICER
LUSAKA REGIONAL HEADQUARTERS
PRIVATE BG RW 21E
LUSAKA

28th December, 2017

The District Education Board Secretaries
LUSAKA PROVINCE

**RE: DATA COLLECTION: RESEARCH RECRUITMENT OF TEACHERS
WORKING WITH LEARNERS WITH AUTISM SPECTRUM DISORDER IN
LUSAKA PROVINCE**

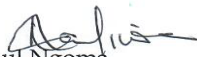
The above subject matter refers.

I write to introduce Mr Joachim Nyoni from Ministry of General Education headquarters who is a PHD student with the University of Cape Town, who is currently carrying out a research study titled "A participatory Action Research project on Family Needs: Experiences of Formal and informal support services available among Zambian parents of children with Autism Spectrum Disorders (ASD). HREC number (113/2017) UCT and ref 2017 - Oct - 023 ERES.

The purpose of the study is to identify family support needs of children with ASD and also to find out additional services they need.

In view of the above, I write to request your office to give him the support as he conducts his research.

I look forward to your usual support.

PP 

Paul Ngoma
PROVINCIAL EDUCATION OFFICER
LUSAKA PROVINCE

/mp

Appendix G: Authorisation Letter from Provincial Health Director

All Correspondence should be addressed to the
Provincial Medical Officer -
Telephone: +260 211 256815
Telefax: +260 211 256814



REPUBLIC OF ZAMBIA MINISTRY OF HEALTH

In reply please quote

File No.

PROVINCIAL MEDICAL OFFICER
P. O. BOX 32573
LUSAKA

26th February, 2018

Nyoni Joachim
University of Cape Town
Faculty of Health Sciences
Dept of Health Rehabilitation
South Africa

**Re: Data Collection :Research Recruitment of Professionals and Families
Supporting children with Autism Spectrum Disorder in Lusaka
Province**

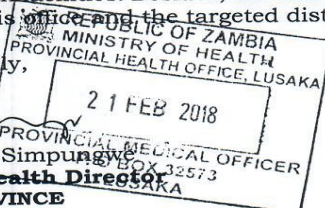
Refer to the above subject matter.

My office is in receipt of your letter dated 18th February in which you are requesting for authority to collect data in Lusaka, Chilanga, Kafue Chongwe and Rufunsa district on your research study titled, "A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services Available among Zambian Parents of Children with Autism Spectrum Disorders (ASD)".

I am glad to inform you permission has been granted for you to collect data in the selected districts. However, during the period you will be conducting your research there must be minimum interruption to health service delivery in the targeted health facilities. Besides, the final report of your research you must also share with this office and the targeted districts where the research will be done

Yours faithfully,


Dr. Kakungu Simpungwe
Provincial Health Director
LUSAKA PROVINCE



cc. Lusaka District Health Director – Chongwe
cc. Lusaka District Health Director – Kafue
cc. Lusaka District Health Director – Rufunsa
cc. Lusaka District Health Director – Lusaka
cc. Lusaka District Health Director – Chilanga

Physical Address: 3 Saise Road, Longacres, Lusaka, Zambia

Appendix H: Invitation Letter to Stakeholders Meeting on ASD Family Needs



School of Health Science,
Department of Health and Rehabilitation
Cape Town, South Africa.

11th June, 2018

Dear Sir/Madam

RE: INVITATION TO A STAKEHOLDERS MEETING ON FAMILY NEEDS; EXPERIENCES OF FORMAL AND INFORMAL SUPPORT SERVICES AMONG ZAMBIAN FAMILIES OF CHILDREN WITH AUTISM

With reference to the above subjected matter captioned;

We are hereby inviting you to a half day workshop and discussion meeting that will be held at Bauleni Special School Project on Friday 15th June, 2018, arrival time is 08:00hrs. The purpose of the meeting is as follows;

- Present the findings of Phase One as expressed by both Professionals and Parents/Caregivers of children with Autism on their Experiences of Formal and Informal Support Services within Zambia particularly Lusaka Province.
- Develop an Action Plan based on the themes and Sub -themes generated from Phase One Project. The Action plan will be implemented in Phase three.

Your positive response, presence and contribution towards this study will be highly appreciated. Kindly find attached a copy of the program and the information sheet for this particular study.

For further information contact the following:

Ministry of General Education

Directorate of Early Childhood Education

P.O. Box 500093, Lusaka

Email: joachimnyoni@gmail.com

Cell: +260977318702/+260955318702

Henry Mwanza_0975582278 and Ms. Susan Chungu -0979424339 (Research Assistants)

I look forward to your participation.

Joachim Nyoni (Ph.D. Student)

Appendix I: Focus Group Guiding Rules



School of Health Science,

Department of Health and Rehabilitation

Cape Town, **South Africa.**

Dear Participants,

I would like to thank you all for coming and for your willingness to participate in this Phase. I should believe all of us have signed our consent forms. If you still have any questions, please, feel free to ask me and let me know.

For us to work well, we need to come up with guiding rules as a team. I would suggest that we come up with guiding rules for our meeting to run smoothly. We do not want anyone to disadvantage others as we share our ideas and experiences. I will ask one of my co-researchers to write down all agreed rules or what we shall call support group confidentiality code of conduct.

How do we protect our confidentiality during focus group discussions? Any suggestions. I have already assured you that I will keep your information with all the confidentiality it deserves. If I misconduct myself and break the confidentiality that causes you to feel greatly hurt, you are free to report me to my supervisors on the contact addresses written on the information sheet.

I would suggest that we come up with a code of conduct too to guide us on confidentiality. All the rules that we shall agree on here will guide our conduct within and beyond the group. These are some of the rules which we are going to follow

1. No mini-meetings within a meeting
2. No coercing others to stop the project
3. Keep time and participant fully
4. All sensitive information about the child or parent that is shared here should not be discussed outside this meeting with any person, media such as Facebook, WhatsApp, Twitter, Radio Television etc. or its agencies.
5. We bracket our status and work as a team as parents/professionals who have a common goal of identifying family support needs.

6. Any information that reaches us privately and is confidential about someone or of an organisation that is not present here, should not be taken outside to inform them of what was said about them.

7. We will stick to the topic at hand, and no one will be allowed to use this forum to advance their agenda in politics or religious mileages.

Are there any other rules which you feel we need to add and consolidate?

I hereby agree to follow the code of conduct during the meetings.

Appendix J: Information Sheet for Parents



School of Health Science,

Department of Health and Rehabilitation

Cape Town, **South Africa.**

Ministry of General Education

Directorate of Early Childhood Education

P.O. Box 500093

Lusaka

Email: joachimnyoni@gmail.com

Cell: +260977318702/+260955318702

Dear Participant,

Introduction

My name is **Joachim Nyoni**, a PhD student in Disability Studies at the University of Cape Town, School of Health Sciences, Department of Health and Rehabilitation.

Title of the study: A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services among Zambian Families of Children with Autism Spectrum. HREC number (113/2017).

Purpose of the Study

I am very much interested in understanding the experiences of families of children with Autism Spectrum Disorder (ASD) in accessing formal and informal services for their children and what future support they would need. This research will promote empowerment skills of advocacy, awareness, self-determinism, and emancipation amongst parents. It is anticipated that through this study your needs will be identified for future support service provisions. Findings from this study will support and inform policymakers and other stakeholders to develop policies and strategies that aim to alleviate challenges faced by parents in accessing quality services for their children.

Why have you been invited to participate?

I have identified you because of your knowledge and lived experiences of caring, raising and supporting a child with ASD which needs to be shared and is very relevant to this study. You will not be alone. I have identified fellow parents with similar challenges who are willing to be part of this study.

Information about this research

This research study is a Participatory Action Research (PAR) where the researcher, parents, and professionals actively work together to find a solution to a problem that affect you as a parent of a child with ASD (family support needs of children with ASD). In this study, you need to be committed to attending focus group discussion sessions, individual interviews, and group meetings at convenient venues. This study is divided into three parts or Phases. Phase 1, 2 and 3.

Phase 1: You are expected to participate in a focus group session that will be held in your district. The purpose of the Focus group meetings will be for you (parents) to share your lived experiences with fellow parents on challenges that you face in accessing formal and informal support services.

Phase 2: Parents and professionals are going to work together to identify themes. You are going to be involved in focus group discussions sessions and group meetings. You and professionals are going to draw up an action plan for the identified problems and suggest how they can be implemented.

Phase 3: In Phase 3, You and the researcher will implement the activities planned in phase 2. During this phase, you are expected to be involved in focus group discussion sessions, stakeholder's meetings, pair work, and individual work. Individual interviews may be done during reflective learning. Professionals may only be invited at your request as resource persons. Towards the end of Phase 3, a general meeting will be called for all participants, parents, and professionals to come together and share experiences learned during the project and plan on how to sustain the project after this research project is over.

What will be required of me?

You will be expected to take part in all planned activities and meetings. The project will run for **six** months. However, these meetings will not be on daily basis. During our first meeting, I will explain the aim and objectives of the research study project. In Phase 1 and 2, you are expected to participate in a focus group discussion session lasting 40-60 minutes in duration at a convenient venue in your community. In Phase 3, five focus group sessions running for 5 months, one meeting per month will be conducted. During this period, I request that you spare 2-4 hours for each meeting for various activities such as FGD and pair work. We may have other shorter follow-up meetings as a need arises. The meetings will be conducted at convenient venues both in rural and urban districts that we are going to agree upon.

During FGD, I will guide the discussion with the assistance of two research assistants. I am going to provide a venue that will be safe, comfortable, and away from noise or other disruptions. I will be happy to answer the questions that you may have about the research. Later, we shall ask you some questions on your experiences of formal and informal support services in Zambia, the barriers to access support services and what future services you would like your child to access. We are going to have other activities on advocacy that will come from your planned activities in phases 2 and 3. Be assured that we are not going to ask you questions about your private life or practices that may make you uncomfortable.

During each phase, you will be expected to sign a consent form in English or a translated local languages version of (Chi Nyanja, Chi Tonga /Soli and Chi Bemba). Research assistants will read the translated version for parents who are illiterate in the language familiar to them.

You will be further required to sign the attendance register during each meeting and session. I request to use audio, video cameras and get photos during the sessions under your consent. This will help the researcher capture as much information as possible that I will use during the research write up. You are, however, free to allow me to use only audio or both, during the activities or stop me not recording anything on issues that you feel are sensitive and need not be recorded.

Are there some risks in taking part in this research?

There are minimal risks involved in this study as compared to benefits. Some of the risks involved may include emotional and economic risks. In an event that some negative emotions arise during the session, the researcher or his research assistants will provide timely counselling and if further counselling therapy will be needed. I will make follow-up counselling sessions outside the programs. The researcher will be mindful of economic risks that may arise, mainly to participants that will be engaged in phase 2 and 3 sessions of the project. A token of appreciation will be given in form of a food hamper worthy K200. During the meetings, light refreshments and transport refunds will be provided too.

What are the benefits of taking part in this study?

This research may have no material benefits as you need to volunteer. You are free to withdraw at any time without any reprisal. Do you have other options or ways on your own that you think could help address the challenges that you and your child face in accessing formal and informal

support services if you don't volunteer to be part of the study? How do you think the barriers to support services for your child can be improved and by who?

The benefits are that your contributions to this study will be valued greatly because the data provided will help policymakers gain advanced knowledge about the family support needs of children with ASD. This will help them make an informed decision at the planning and implementation stages. Furthermore, this study could be a platform for future studies on Autism and improve its practice.

Information that will be shared will be treated with all the confidentiality it deserves. I will only break the confidentiality and inform the third person such as health professionals in an event where a person shows signs of committing suicide, child abuse is negligent, not caring for a person suffering from a disease like tuberculosis or a disabled person. All materials will be locked up in my office strong room locker. Audio and video materials will be locked on a password computer. Pseudonyms names will be used in the research write up. I will need your consent for the materials to be kept longer for more than five years and be used by secondary researchers. This is because of the uniqueness of the study which has limited publications in Africa on issues of family support for caregivers of children with ASD. Materials may be accessed by a second person, data analysis personnel. However, only pseudo names will be used on all the files and folders.

Right to Refuse or Withdraw

Your participation in this study is voluntary and you are free not to take part and this will not have any negative impact on you as an individual or your family or the people providing services to you and your child. You are free to withdraw at any time during the project and this will not affect our relationship. The information that you will give us will still be treated with all the confidentiality it deserves even after you have stopped, and it will still be part of the study. At the end of the discussion, I will give you time to reflect on your participation and to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Who to contact?

In an event that you feel unfairly treated by the researcher during the sessions. You can contact the chairpersons of the Human Research Ethics Committee as below:

The Chairperson

The Faculty of Health Sciences Human Research Ethics Committee.

University of Cape Town, Room E52.24, Old Main Building,

Groote Schuur Hospital. Cape Town South Africa:

Telephone number: **+27 021-406 6534.**

In Zambia contact.

The Chairperson Ethics committee, (Professor Munalula-Nkandu)

ERES CONVERGE IRB

33 Joseph Mwilwa Road

Rhodes Park

Lusaka

Tel: 0955 155633/4

E-mail: eresconverge@yahoo.co.uk.

IRB: NO. 00005948 EWA: NO. 00011697

I, therefore, request you to participate in this research project.

I would like to thank you for your time.

This is your copy for your records. Please keep it.

Appendix K: Informed Consent Form for Parents (Phase One)



School of Health Science,

Department of Health and Rehabilitation

Cape Town, **South Africa.**

I have read (or this was read to me by) the information sheet. I agree that the content on the information sheet is clear, and, in the language, I understand very well. I understand the type of study to be done and what is required of me. I feel all my questions were answered. I have not been forced to take part in this study. I have freely volunteered. I am free to withdraw at any time and this will have no consequences for me. I am aware that this project has three Phases. In **Phase 1** and **2**, I will be expected to participate in one-day focus group sessions lasting 40-60 minutes in durations. In **Phase 3**, I will be involved in focus group discussion sessions, stakeholder's meetings which will run for five months. Each session will be lasting 2-4 hours. The meeting for **Phase 1** will be held at a convenient venue in my community (District) that will be communicated to me by the researcher. In this phase, am ready for the activities.

I would like to take part in **Phase 1 only**.

Kindly tick where appropriate

Thumb.[].

Yes. I do accept to take part in the study. Phase1 only

[]

[]

NO. I am not ready to take part in the study [] []

1. Parent Details:

Name:..... Surname.....

Signed.....Date.....

Contact number:

Place/Location.....

2. Witness

Name:.....Surname.....

Signed:..... Date.....

Contact number:.....

Place/Location.....

1. Researcher' Name:.....Surname.....

Signed:.....Date.....

Appendix L: Informed Consent Form for Parents (Phase Two)

I have read (or this was read to me by) the information sheet. I agree that the content on the information sheet is clear, and, in the language, I understand very well. I understand the type

of study to be done and what is required of me. I feel all my questions were answered. I have not been forced to take part in this study. I have freely volunteered. I am free to withdraw at any time and this will have no consequences for me. I am aware that this project has three Phases. In this Phase, I will be involved in focus group discussion sessions, reflective learning, and stakeholder's meetings. Activities in **Phase 2** will run for six months with at least a meeting each month. The duration of each session will be 2-4 hours. I am aware that this could have some emotional and social-economic risks on my side considering the period in which the project will run. The meetings will be held at convenient venues which parents and the researcher will agree upon in rural and urban districts. I am ready and willing to do all activities in Phase 3. I would like to take part in **Phase 2 only**.

Kindly tick where appropriate

Yes. I do accept to take part in the study. Phase 2 only

☐

Thumb

☐

NO. I am not ready to take part in the study

☐
☐

1. Parent Details:

Name:.....

Surname:.....

Signed.....

Date.....

Place/Location.....

Contact number:

2. Witness

Name:.....Surname.....

Signed:.....

Date.....

Place/Location.....

Contact number:.....

Researcher:.....**Surname.**.....

Signed:.....Date.....

Appendix M: Information Sheet for Professionals (Phase One)



School of Health Science,

Department of Health and Rehabilitation

Cape Town, **South Africa.**

Ministry of General Education

Directorate of Early Childhood Education

P.O. Box 500093

Lusaka

Email: joachimnyoni@gmail.com

Cell: +260977318702/+260955318702

Dear Participant,

Introduction

My name is **Joachim Nyoni**, a PhD student in Disability Studies at the University of Cape Town, School of Health Sciences, Department of Health and Rehabilitation.

Title of the study: A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services among Zambian Families of Children with Autism Spectrum Disorders. HREC number (113/2017).

Purpose of the Study

I am very much interested in understanding lived experiences of families of children with autism spectrum disorder (ASD) in accessing formal and informal services for their children and what future support they would need. This research will promote empowerment skills of advocacy, awareness, self-determinism, and emancipation. I hope that through this study your needs will be identified for future quality service provision to families and children with ASD. Results from this study will support and inform policymakers, parents of children with ASD and other concerned professionals to work together and advocate on the rights of both parents and children with ASD to access quality formal services.

Why have you been invited to participate?

I have identified you because of your knowledge and experience in providing formal services to parents and children with ASD. You will not be alone. I have also identified other professionals from various institutions and organisations that directly support ASD.

Information about this research

This research study is Participatory Action Research (PAR). The researcher, parents, and professionals actively work together to find a solution to a problem affecting the community (Access to quality formal and informal support needs of children with ASD). In this study, you need to be committed to participating in an individual Semi-structured interview, focus group discussion sessions and stakeholder's meetings. This study is divided into three parts or Phases: Phase 1, 2 and 3.

Phase 1: You are expected to participate in an individual semi-structured interview. The focus of the interview is to get insight and experiences on challenges that you face in providing formal services to children with ASD and what you think need to be done to improve future services.

Phase 2, you are going to meet parents of children with ASD and other professionals with whom you are going to work together. You will be involved in focus group discussions sessions and a group meeting with other professionals and parents. The objective of this phase is to *take the research further, reflect on research, Priorities the themes and come up with an action plan on how best family support needs can be met. Here you will be more of a resource personnel.*

Phase 3: You will only be involved in this phase at the invitation of the parents as any need arises. Towards the end of Phase 3, you will be invited to a general discussion meeting where you are going to share your experiences on what you learned, how to put the study into policy practice and what you think needs to be done to sustain the project.

What will be required of me?

You will be expected to take part in all planned activities and meetings. The project will run for **six** months. However, this meeting will not be on daily basis. Your major role will be in Phase 1 and 2 where you will be involved in two activities. In Phase 1, you will be involved in one day 40-60 minute's semi-structured interview at your office or at a convenient venue to be agreed upon. In Phase 2, you will be expected to participate in a one-day focus group session which will run between 40-60 minutes at a venue in Lusaka District to be communicated to you by the researcher. In Phase 3 activities that you will be a resource, a person will last between 2-4 hours.

During all meetings, you will be required to sign the attendance register. This will assist the researcher in the research study write up. I seek consent from you to use audio, video cameras and get some photos during the sessions. This will help me to get as much information as possible for the research study write up.

Are there some risks in taking part in this research?

There are minimal risks involved in this study as compared to benefits. Some of the risks involved may include emotional and economic risks. In an event that some negative emotions arise during the session, the researcher or his research assistants will provide timely counselling and if further counselling therapy will be needed, I will provide it even after the sessions. I will make follow up for such persons. Light refreshments and transport refunds will be provided to you.

What are the benefits of taking part in this study?

This research may have no material benefits voluntarily. You are free to withdraw at any time without any reprisal. However, the benefits will be that your contribution to this study will be valued because it could provide an opportunity for interested stakeholders such as policymakers, institutions providing services to families of ASD children could help advance their rights. Furthermore, this study could be a platform for future studies on Autism and improve its practice. Do you have other options or ways on your own that you think could help address the challenges that you face in providing formal support services if you don't volunteer to be part of the study? How do you think the barriers to support services for families of children with ASD can be improved and by who?

I will need your consent for the materials to be kept longer for more than five years and be used by secondary researchers. This is because of the uniqueness of the study which has limited publications in Africa on issues of family support for caregivers of children with ASD. Materials may be accessed by a second person, a data analysis personnel. However, only pseudo names will be used on all the files and folders. Information that will be shared will be treated with all the confidentiality it deserves. Materials will be locked up in my office strong room locker. Audio and video materials will be locked on a password computer. Pseudonyms names (not the real name of participants) will be used in the research write up. Materials will be transferred to the University of Cape Town for safekeeping with the supervisors and after five years will be destroyed.

Right to Refuse or Withdraw

Your participation in this study is voluntary and you are free not to take part and this will not have any negative impact on you as an individual or your family or the people providing services to you and your child. You are free to withdraw at any time during the project and this will not affect our relationship. The information that you will give to us will still be treated with all the confidentiality it deserves even after you have stopped, and it will still be part of the study. At the end of the discussion, I will give you time to reflect on your participation and to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

In an event that you will feel unfairly treated by the researcher during the sessions you can contact Prof Marc Blockman, the Chairperson of the Human Research Ethics Committee at the following address:

The Chairperson,

Faculty of Health Sciences Human Research Ethics Committee

The University of Cape Town. Room E52.24,

Old Main Building, Groote Schuur Hospital. Cape Town South Africa.

Telephone number: +27 021-406 6534

In Zambia. You can contact:

The Chairperson Ethics committee, (Professor Munalula-Nkandu)

ERES CONVERGE IRB

33 Joseph Mwilwa Road

Rhodes Park

Lusaka

Tel: 0955 155633/4

E-mail: eresconverge@yahoo.co.uk.

IRB: NO. 00005948 EWA: NO. 00011697

I, therefore, request you to participate in this research project.

I would like to thank you for your time.

This is your copy for your records. Please keep it.

Appendix N: Consent Form for Professionals (Phase One)

I have read (or this was read to me by) the information sheet. I agree that the content on the information sheet is clear, and, in the language, I understand very well. I understand the type of study to be done and what is required of me. I feel all my questions were answered. I have not been forced to take part in this study. I have freely volunteered. I am free to withdraw at

any time and this will have no consequences for me. I am aware that this project has three Phases. In **Phase 1** and **2**, I will be expected to participate in one-day focus group sessions lasting 40-60 minutes in durations. The meeting for **Phase 1** will be held at a convenient venue in my community (District) that will be communicated to me by the researcher. In this phase, am ready for the activities.

I would like to take part in Phase 1 only.

Kindly tick where appropriate.

Yes. I do accept to take part in the study. Phase1 only

☐☐

NO. I am not ready to take part in the study

☐☐

1. Parent Details:

Name:..... Surname.....

Signed.....Date.....Contact number:

Place/Location.....

Place/Location.....

3. Researcher:.....Surname.....Signed:.....Date.....

Appendix O: Interview Schedule for Families (Phase One)

Parent Participant No



A. DEMOGRAPHIC DATA FOR FAMILIES.

Tick where appropriate

1. Parent/Care giver's Gender: Male ☐ Female ☐
2. Age of the Participant
3. Child's First Name with ASD: Child's Family Name:.....
4. Date of Birth for the child with ASD: Sex: Male ☐ Female ☐.

If you have more than one child with ASD indicate their details on a separate sheet or at the back of the paper.

5. Relationship to the Child/s with ASD

Biological father ☐

Biological mother ☐

Step father ☐

Step mother ☐

Extended family (Grandparents, Sister, Aunties/Uncles).....

6. Please indicate whether from the Paternal or Maternal side.....

7. Are both parents of the child with ASD still living? Yes ☐ No ☐

8. Does the child go to school? Yes: ☐ No : ☐. If yes:

Name of school:.....

9.Type of School: Special School/Unit ☐ Ordinary(Mainstream) ☐ Special and Ordinary ☐

Others.....

10. Agency of the School: Public (GRZ) ☐ Faith-Based (Grant Aided) ☐ Private ☐

Community-Based ☐ Others..... ☐

B. BACKGROUND INFORMATION

1. Marital status: Married ☐ Divorced ☐ Separation ☐ Single ☐ others ☐

2. What is your highest school qualification?

Never went to school ☐ Grade1- 7 ☐ Grade 8 and 9 ☐ Grade 10-12 ☐

College ☐ University ☐

3. Highest school level qualification of the spouse if married.

Never went to school ☐ Grade1- 7 ☐ Grade 8 and 9 ☐ Grade 10-12 ☐
college ☐ university ☐

Are you currently doing any studies? Yes ☐..... No ☐

4. What is your Occupation?

If married what is the occupation of your spouse?.....

5. What is your Household Monthly Income in Kwacha?

Below K3,300 ☐

K3, 300 – K9 000 ☐

K10, 000 – K20, 000 ☐

K20, 000 and above []

Not ready to reveal []

6. What is the Household Monthly Income of the spouse/ in Kwacha if you are married?

Below K3,300 []

K3, 300 – K9 000 []

K10, 000 – K20, 000 []

K20, 000 and above []

Not ready to reveal []

7. Type of employment. (If you are employed as in 7a and 7b and 7c, skip and go to question 8)

a. Paid Employee: A person who works for a public or private employer and receives remuneration in wages or salaries either in cash or in kind. []

b. Self-employed: A person who operates his or her economic enterprise(s) and hires no employees []

c. Entrepreneur: A person who runs their own business and may have employees (Companies, chain stores, shops, taxis, Minibuses Furniture, internet café)

d. Unpaid Family Worker: Refers to a person who normally assists in the family business or farm but does not receive any pay or profit for the work performed. []

e. Small scale agricultural household: Refers to a person growing crops, livestock/poultry owning, fish farming or a combination of any of these [].

f. Housewife: Unemployed []

g. Unemployed (unskilled Labour) Maids, Garden workers, []

h. Others specify.....

8. Place of employment

9. Current Position

10. What type of employment agreement are you on?

a. Contract []

b. Permanent and Pensionable []

c. Part-time and short-term contract (Voluntary community teacher, Builder, Plumber) []

d. Others Specify).....

11. Number of biological children living in the home (below 18 years) Male []

Female []

12. Household size.....

13. Number of children in the household with other disabilities. Male [] Female []

14. How long have you been caring for a child with ASD?

Below one year []

1- 3years []

3-6 and above []

7 and above []

15. How old was the child when He/she was diagnosed with ASD?

0-1 year []

2-3 years []

4-5 years []

6-7 years []

8 years and above []

If you have more than two children with ASD, please give details of the child/children on a separate paper or write at the back of the paper

16. Religious background.

Christian []

Muslim []

African tradition []

Hindus []

Not ready to reveal []

Other (Specify).....

B. FOCUS GROUP AND REFLECTIVE SESSIONS

Below is an interview guide for the focus group for parents with children with ASD.

The researcher may not follow the order of the way questions as outlined but will make sure that at the end of the session, all the questions are covered.

1. Introduction.

My name is **Joachim Nyoni**, a PhD student in Disability Studies at the University of Cape Town in South Africa, School of Health Sciences, Department of Health and Rehabilitation. I am doing research entitled, *A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services among Zambian Families of Children with Autism Spectrum*. The purpose of this study is to understand the experiences of families of children with autism spectrum disorder (ASD) in accessing formal and informal services for their children and what future support they would need. This research aims at promoting empowerment skills of advocacy, awareness, self-determinism, and emancipation.

Focus Group Guiding Rules (Confidentiality code for the group)

The confidentiality code for the group and the ground rules are guidelines that are going to protect everyone to express oneself without any fear of victimisation from other members.

They also respect other members' rights during the interactions. We are going to go through the confidentiality code for the group together which I have distributed to you according to the language which you understand well. You are free to suggest some additions. Please feel free to ask questions where you do not understand well.

1. Now it's time to introduce each other. Please tell us your
 - i. Name,
 - ii. What you do.
 - iii. The name of the child with ASD.
 - iv. Where you are coming from.
 - v. Why you are part of the group session.
 - vi. What do you expect to gain or contribute to the group?

Please, welcome to our focus group. Before we start the interview, I will explain what I mean by family support needs for families of children with an autism spectrum disorder. *These are resources, access to formal and informal services, information and strategies that are aimed at promoting and supporting the personal well-being of the child and their parents.* Now that I have explained to you. Let us discuss the following questions:

2. Defining Support Needs and Available Services.

- i. What does the term family support needs mean to you as an individual?
- ii. Reflect and mention some of the needs that you require.

3. Experiences of Families on the status of Services, Resources Available, Training and Transitional Support offered to Parents at Peri, Pre-and Post-Diagnosis

- i. More reflectively, let us talk about how you look at current services and resources that are offered or were offered to you by various professionals, families, and the community at pre, peri and post-diagnosis.
- ii. What did you find helpful or not helpful with the current support services?
- iii. Explain to me whether you need any training on childcare and management in the past last six months. Did you get this service? How were your experiences? How did you feel before and after accessing the services?
- iv. *What are some of the barriers you have faced in meeting the support you need?*

- v. What are the current challenges in providing care and support to your child in the current situation?
- vi. How do you deal with these challenges?
- vii. In your opinion, which services (formal and informal) would you need that would help you care for a child well?
- viii. How important is this current study to you?
- ix. Are there any specific names of individual professionals or institutions you would like to meet or to be part of the study?
- x. Now let us talk about inadequacies in areas of empowerment skills. In which areas would you consider yourself to have some inadequacy in respect to family support services?

4. Parents support group as advocates for change.

Now let us talk about ASD family support groups that you have heard of, know, or belong to in your community.

- i. In what ways can ASD community family support groups be actively involved in service delivery?
- ii. How can community family support groups be strengthened and sustained to help bring about change in the provision of quality support services to both the child and parents/caregivers?
- iii. Tell us your story (lived experiences) about searching for services for your child with ASD.
 - a) How was your relationship with professionals and the community?
 - b) What transitional Support was offered to you at Peri, Pre-and Post-Diagnosis by both formal and informal service providers?
 - c) How much Support do you receive from immediate family members? the community and the religious organisation?
- iv. Imagine, if all wishes were to come true and you had all the powers to change anything about family support programs and services, what would be different?
- v. Any other information that you think we need to share about family support needs?

THANK YOU FOR SHARING THIS INFORMATION

Appendix P: Interview schedule for Families (Phase Two)



School of Health Science,

Department of Health and Rehabilitation

Cape Town, **South Africa**

Researcher: Nyoni Joachim (Student)

Supervisor: Dr Judith McKenzie

Institution: University of Cape Town

Institution: University of Cape Town

Department: Health and Rehabilitation

Department: Health and Rehabilitation

Cell: +26 0977318702

Phone: 0214066318/Cell+27835000464

Family supporting needs and their plan of action

You are all welcome to Phase 2. It is good to meet again and begin another phase. I would like to thank you all for accepting to be part of this phase. I also welcome our professionals from various institutions whom you will work with during this phase. I should believe we all have signed our consent forms and if you still have questions about the study, you are free to still ask me. Please be reminded that at the end of this phase, we are going to have a short activity in which I will talk about the next activity in phase 2 and your participation. Now let me first present the results from a study conducted in Phase 1. I will start with those from parents and end with professionals.

Let us discuss these questions in groups. Our questions will be guided by what is called the Strength, Weakens Opportunities and Treats activities (SWOT). I will explain more on what needs to be done and what SWOT means.

1. What are your desired needs from professionals and what future action (programs/projects/activities) need to be taken so that your support needs are met? What do you think are the strength of the themes you have selected in relation to family support needs?
2. How best can society and the community be made aware of challenges that families of children with ASD face as they try to meet their needs?
3. What role would you play to bring about community involvement in meeting your support needs?
4. What additional future formal and informal support services have you identified and are there any opportunities to family support programs to the community?
5. Would you be willing to learn new skills and knowledge on advocacy for your child that may help policymakers come up with laws that do not marginalise you as parents?
6. What is your comment about community-based programs where you as parents come together to teach each other, share experiences plan, and design programs that focus on family support need for your children here in Lusaka province?

7. Develop an action plan based on the themes we have selected. Indicate in your schedule of activities who will do the work, when where and how. You also indicate the time frame and possible dates.

Thank you for taking part in this activity and for your time.

Appendix Q: Interview Guide for Professionals

Professional Interview Guide (PIG) No...



(A) DEMOGRAPHIC DATA FOR PROFESSIONALS

Tick as appropriate

1. Gender: Male ☐ Female ☐

2. Highest qualification:

Grade 7 and below ☐ Grade 12 and below ☐ Grade 12 Certificate ☐

Certificate ☐ Diploma ☐ First degree ☐ Master's degree ☐ PhD ☐

Others specify

3. Are you currently pursuing any studies? Yes: ☐ No: ☐. If Yes mention it

4. Place of employment.....

(Please specify whether it's under GRZ, or Quasi-Government, NGO, International Organisations).....

5. Years in service:.....

6. Current position:

7. Type of employment agreement.

A. Contract basis []

B. Permanent and Pensionable []

C. Part-time []

Others

7. Years of experience in the current position.....

8. What is your occupation?.....

9. Years working with children with ASD.

Below 1 year []

1-5 years []

6- 10 years []

11 and above []

10. Certification or course specifically on ASD?

Certificate of attendance []

Certificate []

Diploma []

Degree []

Masters []

Workshop/seminar without certification []

Doctoral studies with courses related to ASD []

Name of Doctoral programme.....

Others.....

(B) INTERVIEW GUIDE (OPEN-ENDED QUESTIONS) FOCUS GROUPS

This interview guide is designed for professionals that work with families of children with autism spectrum disorder (ASD). Below is an interview guide that is designed for professionals that work with families of children with ASD. I may not follow the order of the questions as outlined but will make sure that at the end of the session, all the questions are covered. Professionals will be guided by the following questions:

1. Introduction.

Please welcome to our face-to-face interview. My name is **Joachim Nyoni**, a PhD student in Disability Studies at the University of Cape Town in South Africa, School of Health Sciences, Department of Health and Rehabilitation. I am doing a research study entitled, *A Participatory Action Research Project on Family Needs: Experiences of Formal and Informal Support Services among Zambian Families of Children with Autism Spectrum*. The purpose of this study is to understand the experiences of families of children with autism spectrum disorder (ASD) in accessing formal and informal services for their children and what future support they would need. This research aims at promoting empowerment skills of advocacy, awareness, self-determinism, and emancipation amongst parents/caregivers of children with ASD.

Before we start the interview, I will explain what I mean by family support services for families of children with an autism spectrum disorder. *These are resources, access to formal and informal services, information and strategies that are aimed at promoting and supporting the personal well-being of a child and their parents*. Now that I have explained to you, let me ask you the following questions:

1. Professional's work experience.

Now let us talk about your professional life:

- i. Tell me your name,
- ii. Where you work,
- iii. The discipline of specialisation and type of services you provide in general. (Tell me who you are)

2. What does the term ASD support services mean to you?

- i. In line with your discipline, tell me how you work with children with ASD and their families.
- ii. In a more reflective manner, how much support have you received from your fellow professionals and administrators towards support to ASD?
- iii. How often do you have Continuous Professional Development meetings (CPDs) on ASD?
- iv. Would you consider yourself as an adequately trained person to work with families and children with ASD? What makes feel so or not?

3. Current Support Services Available.

- i. Explain to me your experiences with current available formal support service provisions to families and children with autism spectrum disorder (ASD) at your institution.
- ii. What method (s) do you use to provide services to families of children with ASD?
- iii. As a professional, describe the current service available to families of children with ASD.
- iv. How would you describe tools used for the diagnosis of ASD?
- v. Mention some of the tools available at your institution.
- vi. More reflectively, let us talk about some of the barriers that you face in meeting the needs of families of children with ASD.
- vii. What type of action do you think need to be taken to reduce these barriers?
- viii. How much therapeutic intervention does the child need?
- ix. What are some of the barriers that you feel parents face in accessing the services?
- x. How do you think families cope up with these barriers?
- xi. What type of training would parents/caregivers need that would promote advocacy?
- xii. What course of action do you use to address current family supports needs?

- xiii. How would you describe your relationship with families of children with ASD that come for service?
- xiv. Are there any multi-disciplinary teams that can easily be accessed by parents/caregivers in their respective communities?

4. Future Support Services.

- i. Where are the gaps in service delivery?
- ii. What future support services do you think need to be put in place?
- iii. Who do you think are the future key stakeholders that can help families bring about policy change, awareness, and advocacy to both families and the general community?

5. Family Community Group Support Services

- i. Where would you refer parents for support services after the child is diagnosed with ASD?
- ii. How coordinated are the services for families of children with ASD?
- iii. Kindly explain to me the type of intervention that you think is helpful to a child with ASD, which parents may need to know and be trained in?
- iv. More reflectively, in what ways can Professional –Community Family support group's collaborations serve as models in promoting parents' empowerment skills of advocacy, awareness, self-determinism and emancipation for this cause?
- v. How can Professional- Community family support groups be strengthened and sustained to help bring about change in the provision of quality support services to you as a professional, the ASD child and parents/caregivers?
- v. All things equal, what support programs and services, what would you do differently?
- vi. Any other information that you think you would like to share about family support services?

Thank you for your time

Appendix R: Attendance Register

Date Venue

Time.....

NO	First Name	Surname	National Registration Card number (NRC)	Cell number	Sign

Appendix S: Human Ethics Course



Appendix T: Newspaper Article

Monday September 22, 2018

www.diggers.news

Local News 5

By Thomas Mulenga

The term 'autism' may not only be strange to ordinary citizens who have not stepped in a medical lecture theatre, but also to the men and women who have spent years dismantling huge books of medical theories. However, as strange as the name may sound, 'autism' is a common condition across the world, and Zambia is not an exception. As the world is still in the dark on the causes of autism, one Zambian is going against odds, leading the way to find best ways of taking care of 'autistic' children.

Joachim Nyoni, a Zambian PhD student at the South African University of Cape Town, in the School of Health Sciences, Department of Health and Rehabilitation, is leading a research project in Zambia, seeking to establish the challenges faced by parents and other stakeholders in taking care of children with autism. Before giving a professional definition of autism, Nyoni confirms that the condition is not very well known in Zambia, hence the need to delve into empirical evidence by conducting research on the condition.

Zambian scholar leads research on Autism, IGO steps in with awareness

"I am doing a study on disabilities, more to do with issues of health. This study is a participatory action research trying to look at available services for families with children living with autism. Autism is not a very well-known disability in our country, but in other countries, especially the developed countries, people are aware of it. But a survey from a Zambian perspective shows that very few people know and understand what autism spectrum disorder is. Autism is a neuro developmental disorder, which affects the child's communication aspect, the child has communication deficit,

language deficit and even social interaction is affected. "These children have different characteristics, some of them have repetitive behaviour, for example, an autistic child you may find instead of playing with a toy car in a normal way that any other child does, he may be playing with wheels and if he wants something he may continuously stick to that, so they have that stereotype of behaviour. Of course, some of them are very intelligent children," Nyoni says. The ignorance about the condition, especially among people who have flipped medical books, the doctors, is a source of

worry for Nyoni. His worry is that if medical professionals do not know about autism, there is no way they can care to dedicate their efforts in finding the cure and ways in which to take care of autistic children. "The research is in three phases: in the first phase, I have been working with parents to identify the challenges they have in accessing the services that would help to take care of these children, what future support services would they need; who are the stakeholders who would help to bring about advocacy and self-determinism. So, I have interviewed parents from both rural and urban areas

within Lusaka Province. I have also interviewed professionals, mainly those from Ministry of Health, Ministry of Education and the Department of Social Welfare. I have also interviewed policy-makers to find out the challenges they have as professionals. Some of the professionals, including doctors do not know about autism. Go to the school of medicine, there is a very small component about autism and a lot of students don't know autism. If we have students who are learning medicine do not learn more about autism, then it's a challenge; there are very few doctors who have ventured into this aspect," Nyoni added.

Nyoni, a University of Zambia (UNZA) masters graduate in psychology, said his research is participatory action-based, which is also raising awareness and promoting advocacy for recognition of autism as a serious, independent health condition that should be given serious attention by all stakeholders. He added that the study is also seeking to establish the knowledge that different stakeholders that include medical professionals, teachers, policy makers and parents, have about autism.

"My research is a participatory-action research; I am looking at the services available to families of children with autism. My thinking is, 'what is it which professionals know about autism?' 'What is it which they don't know about autism?' 'Do we have any statistical data about the number of children with autism?' The answer is no! Go to Central Statistical Office (CSO), there is nothing; go to Ministry of Health itself... information is only found in the (assessment) centres; there is no database where somebody can go and get the number for children with autism. If you go to Ministry of Education, you will find the number of visually-impaired, they have the number of those who are deaf, but autism is silent, it is embedded in the intellectual disabilities instead of bringing it out."

Delving into the details about the condition, Nyoni explains that autism affects boys more than girls. "Research shows that one in every five of autistic children is a girl, and four in every five are boys. So, it catches more into the boys as compared to girls. It's a spectrum, which means that some of them maybe on the higher side in terms of behaviour, in terms of hyper-activeness, intelligence, while others maybe on the lower side. You may find that even their performance in school maybe low. One thing about these children is that, it's difficult when you meet them in the streets, you can't know that

this is an autistic child," Nyoni observes.

He further stated that autistic children are at a higher risk of social vices, such as rape and general violence, as some people may take advantage of their condition.

Nyoni added that based on research, parents with autistic children are more stressed than other parents with children living with other forms of disability.

"Studies have shown that parents of children with autism have more stress than any other disability and yet it is silent, and the numbers are growing. So, here is a disability, which makes people more stressful than any other disability and yet it is silent, and the numbers are growing. So, the aim of this research is to have a clear understanding on how it is to have a child with autism, what are the services that they can access," Nyoni said.

Nyoni did not let the opportunity go without making his honest appeal to government, especially on policy formulation. "Where there is no policy, people will do it at their own will. So, if there is a policy, which says, 'let children be examined according to their interests and their needs' because they have been identified and labeled as autistic children and you have known their characteristics. So, why should you expect them to write the same exam with other children? So, a policy in that direction would help. We are also saying, if you have a sixteen-year child with autism, you go to town or a shopping mall and she says, 'daddy I want to go to toilet, as an adult man, where do I take that child for help, men's toilet or women's toilet? Can't we have the policy for such disabled children, which can look into such needs?' wondered Nyoni.

Meanwhile, Dr. Tamara Chansa Kabali, an UNZA psychology lecturer, who is also one of the founders of 'Mulenga Autism Foundation', an organization advocating for awareness on autism in different parts of the country, said so far, there is no research that has revealed the causes of autism, making it difficult to find the cure for the condition.

Speaking when her organisation held a sensitization meeting at Namalombwe Primary School in Chilamba District, Dr. Kabali, who also has a child with autism, called on parents and other stakeholders to show love and care to autistic children as the surest way of helping them. "Unfortunately, even as we speak, there is no research that has been done that has successfully revealed the causes of autism and if that is the case, then it means there is no cure. Everywhere in the world, in America, UK, there is no established cause of autism, but because here in Zambia where we don't even have advanced facilities, we are more affected. However, studies are ongoing and we hope we get the information. The most important thing is to understand the condition of the child as a family and ensure that all stakeholders, such as teachers, the police, friends and other community members, know the condition of a child so that they don't mistreat that child. Children with autism need more love and care from parents and the family," said Dr. Kabali.

Bridges Limited
WE CREATE VALUE

MANAGERS COACHING BREAKFASTS
With Chilamba Kanyama

Manage Talent and Plan Succession
Develop Leaders from within
G.R.O.W. yourself and subordinates

4th Oct 2018
07:00 - 09:00

VENUE
Radisson Blu Hotel
CHARGES
K580/person

Unlock The Best In Self And Others

Registration: 0211-285998
Email: info@bridges-limited.com

#LEADERSHIPCOLD

Plot 1527, Karooboom Ave, Avondale Complex, P.O. Box 30337 CH
Bridges Limited - Tel: +26021 285998 / 0959 418409 / 0979 561077
fanny@bridges-limited.com | info@bridges-limited.com
www.bridges-limited.com