

**COPING BEHAVIOURS OF FAMILIES OF PRE-SCHOOL  
CHILDREN WITH DISABILITIES: A CULTURAL  
PERSPECTIVE FROM ZIMBABWE**

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<b>DEDICATION.....</b>	<b>III</b>
<b>ACKNOWLEDGEMENT.....</b>	<b>IV</b>
<b>ABBREVIATIONS.....</b>	<b>V</b>
<b>ABSTRACT.....</b>	<b>VI</b>
<b>1.0 - INTRODUCTION.....</b>	<b>1</b>
1.1 – PROBLEM STATEMENT.....	1
1.2 - RESEARCH QUESTIONS.....	1
1.3 - STUDY OBJECTIVES.....	1
1.3.1 <i>General Objective</i> .....	1
1.3.2 – <i>Specific Objectives</i> .....	2
1.4 - ZIMBABWE – FACTS.....	2
1.4.1 – <i>Country Profile</i> .....	2
1.5 – THE TONGA---‘THE PEOPLE OF THE GREAT RIVER’.....	4
1.5.1 - <i>The River Tonga</i> .....	5
1.5.2 - <i>Splendid Isolation</i> .....	6
1.5.3 - <i>Early Years of Resettlement</i> .....	7
1.6 - THE TONGA.....	9
1.7 - ‘Go – THE WATER WILL FOLLOW’.....	10
1.8 - SOCIAL SUFFERING AND POVERTY.....	11
1.8.1 - <i>Comparison with Haiti</i> .....	19
1.9 - CONSEQUENCES OF POVERTY FOR PEOPLE WITH DISABILITIES.....	21
2.0 - LITERATURE REVIEW.....	25
2.1 - DISABILITY AND CULTURAL BELIEFS.....	27
2.2 - THE CONCEPT OF ATTITUDES.....	28
2.2.1 - <i>Beliefs and Attitudes</i> .....	28
2.2.2 - <i>The relationship between social position and attitudes</i> .....	29
2.2.3 - <i>The relationship between life experiences, emotions and attitudes</i> .....	29
2.2.4 - <i>The relationship between attitudes and behaviour</i> .....	29
2.3 - THE AFRICAN PERSPECTIVE.....	30
2.4 - THE ZIMBABWEAN TRADITION.....	31
2.5 - MODELS OF DISABLEMENT.....	34
2.5.1 - <i>The Individual Model of Disability</i> .....	35
2.5.2 - <i>The Social Model of Disability</i> .....	35
2.5.3 <i>ICIDH</i> .....	35
2.5.4 <i>ICF</i> .....	35
2.5.5 - <i>The Model for Coping with Disability</i> .....	36
2.6 - SOCIAL SUFFERING AND STRUCTURAL VIOLENCE.....	36
<b>3.0 - METHODOLOGY.....</b>	<b>39</b>
3.1 - RESEARCH METHODOLOGY AND THEORETICAL APPROACH.....	39
3.2 - THE RESEARCHER.....	40
3.3 - THE RESEARCH ASSISTANT.....	43
3.4 - RESEARCH SETTING.....	44
3.4.1 - <i>Objectives</i> .....	46
3.4.3 - <i>Study population</i> .....	46
3.4.4 - <i>Criteria for Inclusion and Exclusion</i> .....	46
3.4.5 - <i>Sample size</i> .....	47
3.5 - DATA COLLECTION TECHNIQUES.....	47
3.5.1 - <i>In - depth Interviews</i> .....	47
3.5.2 - <i>Participant Observation</i> .....	50
3.5.3 - <i>Focus Group Discussions</i> .....	53
3.5.4 - <i>Triangulated Methods</i> .....	54
3.5.5 - <i>Field Notes: (Diary)</i> .....	56
3.5.6 - <i>Secondary Data: (Documents)</i> .....	56
3.6 - DISCOURSE ANALYSIS.....	57

3.7 - DATA MANAGEMENT AND ANALYSIS .....	58
3.8 - DISSEMINATION OF FINDINGS .....	59
3.9 - ETHICAL CONSIDERATIONS .....	59
3.10 - INFORMED CONSENT .....	60
3.11 – CONFIDENTIALITY .....	60
3.12 - ETHICAL CLEARANCE .....	60
3.13 – LIMITATIONS .....	61
3.14 - INFORMATION GATHERED FROM THE STUDY .....	61
<b>CHAPTER 4 RESULTS.....</b>	<b>64</b>
4.1.1 – CASE OF JOE .....	64
4.1.2 – CASE OF ANNIE .....	64
4.1.3 – CASE OF PETER.....	65
4.1.4 - DISCUSSION OF CASES .....	66
4.2 THE CONCEPT OF MISFORTUNE AMONG THE TONGA .....	75
4.2.1 <i>Witchcraft</i> .....	75
4.2.2 <i>Ancestors' sorrow or anger</i> .....	77
4.2.3 <i>The will of God, natural reasons, or 'just happened'</i> .....	79
4.3 - CHOICE OF FAMILY TREATMENT.....	80
4.4 - IN SEARCH OF A CAUSE.....	81
4.5 - COMMUNITY ATTITUDES .....	84
4.5.1 - <i>A Case of 'Hiding'</i> .....	84
4.6 - THE CONCEPT OF ATTITUDES .....	86
4.7 - LIFE BEFORE CHILD WITH DISABILITY WAS BORN .....	88
4.8 - DISABILITY AS LIFE EVENT OR CRISIS? .....	91
4.9 - LIFE AFTER CHILD WITH DISABILITY WAS BORN .....	93
4.10 - STIGMA, GUILT AND SHAME .....	95
4.11 - FAMILY NEEDS .....	96
4.12 - THE TRADITIONAL HEALER .....	99
4.13 - THE DOCTOR – REHABILITATION TECHNICIAN .....	100
4.14 - THE SPIRITUAL HEALER (CHURCHES) .....	101
4.15 - ROLE OF HEALTH SERVICES .....	103
4.16 - ROLE OF COMMUNITY BASED REHABILITATION: (CBR).....	105
4.17 - THE ROLE OF EDUCATION.....	107
4.18 - COPING WITH CARE .....	110
<b>CHAPTER 5 DISCUSSION.....</b>	<b>113</b>
5.1 COPING.....	113
5.2 SOCIAL SUFFERING .....	120
<b>CHAPTER 6 RECOMMENDATIONS .....</b>	<b>125</b>
<b>BIBLIOGRAPHY .....</b>	<b>128</b>
<b>LIST OF APPENDICES .....</b>	<b>134</b>
APPENDIX 1 THE MODEL .....	134
APPENDIX 2 A MODEL FOR COPING WITH DISABILITY THE SYNCRONE PERSPECTIVE .....	136
MAP OF SOUTHERN AFRICA INCLUDING ZIMBABWE .....	137
APPENDIX 3 INFORMED CONSENT FORM - SHONA .....	138
APPENDIX 4 INFORMED CONSENT FORM- TONGA.....	139
APPENDIX 3 INFORMED CONSENT FORM - SHONA .....	140

## **DEDICATION**

**This study is dedicated to the two great women in my life for their unwavering support and encouragement. To my maternal grandmother Kandarama; and my mother Margaret.**

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## **Abbreviations**

WHO            World Health Organisation

CBR            Community Based Rehabilitation

ADL            Activities of Daily Living

ICF            International Classification of Functioning

ICIDH          International Classification of Impairments, Disabilities and  
Handicaps

[Disabled children have also been referred to as children with disabilities]

## **ABSTRACT**

**Introduction;** this study explores cultural beliefs and coping behaviour of families with pre-school disabled children; using culture as one of its variables. It focuses on the household and sees coping with care for a disabled child as an interlinked aspect of coping with life in general. It has been shown (Ingstad, 1988) that ‘in studies of how families cope with the care of a disabled member, culture has been both a neglected and a misused variable etc.’ This has, for instance, led to theories of crisis and coping behaviour postulating more or less universal patterns of reactions with no reservations made about possible cultural diversities (Caplan, 1981; Cullberg, 1966; 1979). As a result, culture has been used as one of the variables in coping with children with disabilities.

### **Study Objectives;**

- ✚ Beliefs and attitudes held by or exhibited by the families of disabled children as they relate to disability.
- ✚ Effects of caring for a disabled child on the family’s activities of daily living.
- ✚ Factors that may influence the caring of a disabled child; e.g. social, economical and political.

**Methodology;** The study was conducted over a period of four months, from August to November 2005. It was an ethnographic qualitative study that triangulated three methods as follows; 30 in depth interviews, 10 participant observations and 3 focus group discussions. Secondary data as well as field notes were used.

**Results;** Disability was shown to be caused by factors that did not include the immediate family. The blame was put on the extended family, neighbours, ancestors and other causes. The results of the study show culture as one of many factors that influence the opportunity situation from which choices in coping behaviour are made. Previous life experiences in coping with critical life events were of major importance for how parents came to cope with a disabled child. Socio-economic variables as well as individual character and individual resilience were also seen to influence coping with care of a disabled child.

The results show us that the process of coping is shaped by cultural influences through emotional patterning, expectations of life and future, life experiences and available opportunities. It was noted that culture also provides a frame of reference for critical life events and gives a particular content of meaning to the families. The results show the importance of culture as one of the variables to be considered when carrying out studies of coping with disability



## **1.0 - INTRODUCTION**

### **1.1 – Problem Statement**

The reason for carrying out this study was because of the suffering of village women that was noticed by this researcher during a study of looking at the living conditions of people with activity limitations in Zimbabwe (2000 – 2003). The study looked at both urban and rural settings. There was a stark difference in how the families were coping with care of their disabled children. The rural families were seen not to be coping at all. This situation provoked a number of questions in my mind as to how the Tonga ended up the way they were; i.e. so poor and not able to afford basic food among other numerous problems. This resulted in my carrying out this study.

### **1.2 - Research Questions**

The interviews were in the form of three themes;

- ✚ The families' view of disability and its meaning.
- ✚ Family life before the disabled child was born or when disability was noted; as well as the cause of the child's disability.
- ✚ The experience of living with a disabled child.

### **1.3 - Study Objectives**

#### **1.3.1 General Objective**

The major purpose of this study was to investigate cultural beliefs and coping behaviour of families with pre – school disabled children in rural Zimbabwe. In addition, this study gathered information on traditional beliefs about reasons for impairments, as well as attitudes and behaviour towards disabled children and identify factors that are of importance in determining coping ability of these families in general and the problems of disability in particular.

### **1.3.2 – Specific Objectives**

- ✚ The beliefs and attitudes held by or exhibited by the families of disabled children as they relate to disability.
- ✚ The effects of caring for a disabled child on the family's activities of daily living.
- ✚ Factors that may influence coping strategies; e.g. social, economical political, cultural and others.

## **1.4 - ZIMBABWE – FACTS**

### **1.4.1 – Country Profile**

Zimbabwe is a land locked country in Southern Africa and covers an area of 390 580 square kilometers and shares borders with South Africa to the south; Botswana to the west; Zambia to the north; and Mozambique to the east. The results of the census place the current population of Zimbabwe at 11 634 663. Zimbabwe is composed of several ethnic groups. About 98% of the population is African (82% Shona; 14% Ndebele and 2 % other). There are a number of subgroups of the Shona as well as differences in traditions and customs. 1% of the population is mixed, with Asians and Whites composing the remaining less than 1%. Half the population is classified as syncretic (part Christian; part indigenous beliefs), 25 % as Christians, 24% as indigenous, with Muslims and others making up the remaining 1 % (Census of Zimbabwe 2002).

Kariba dam is situated on the borderline between Zambia and Zimbabwe. It is built on the Zambezi River 40 km downstream from the famous Victoria Falls. It is 280 kilometres long and approximately 25 kilometres wide. Completed in 1959, the dam is considered as one of the world's largest dams. It is owned by Zambia and Zimbabwe and was designed as a single purpose hydropower project. The Kariba Lake impounded by the dam is also considered as one of the world's largest man made lakes.

For the last twenty years Zimbabwe has been one of Southern Africa's most prosperous countries. It was the world's third biggest source of tobacco and a bread basket for surrounding countries which often depended on food imports. However, the fast land reform implemented by the government implying the seizure of almost all white-owned commercial

agricultural land, with the stated aim of benefiting black farmers, led to sharp falls in production. By 2003, more than 1/3 of Zimbabweans were thought to be at risk of famine (Europa-Development 2005).

The situation in Zimbabwe has been deteriorating in particular since the run up to the elections early 2000 and has developed from what was originally a political conflict into a very serious economic downturn and a humanitarian emergency, with serious implications for the neighbouring countries in the region. Human rights violations, in particular arbitrary arrests and cases of inhuman treatment and torture of members of the opposition and civil society organizations, have multiplied.

The economic picture is grim as a result of Government mismanagement, fast track land reform effects and drought. According to the International Monetary Fund (IMF) Zimbabwe suffers the highest rate of inflation in the world. The annual inflation rate has now reached 1042% and people are being squeezed by steeply rising prices for everyday essentials (Article from the Zimbabwean Print media: 14 – 05 - 06). The country is struggling to keep its economy functioning normally. Zimbabwe's economy has seen a rapid decline and is suffering from shortages of food, fuel and foreign currency resulting in a flourishing black market.

Housing, education and transport costs have also jumped; while the unemployment rate means that almost 2 out of every 3 Zimbabweans are out of work. Only 4% of industry is operating at full capacity. The economy continues to shrink as there is not much production taking place. For many, life has now turned into a survival game (The Insider – April 2006). The literacy rate is estimated at 76% (Article from the Zimbabwe Herald: 14 – 05 – 06).

The health (extremely high HIV/AIDS infection levels affecting 30% of the adult population) and education systems can no longer provide basic services for the majority of the people. Erosion of professional skills is a major threat to the future resilience of the economy (Europa – Development 2005). New hospital consultation fee recently announced by the government has meant that District hospitals like Binga will be charging USD 1.2 from the USD 0.12 that was in place. The government defended the rise, saying they were part of efforts to improve the quality of service in the hospitals.

The researcher noted that the needs of disabled people in the district are many and basic. They range from ordinary basic human needs like food and clothing to those needs specific to persons with disabilities such as aids and appliances. The district has only one rehabilitation unit at the district hospital and this is not adequate; although not many use it due to financial constraints. Only six wards were covered by community based rehabilitation (1989-1994) but these have since collapsed due to lack of resources. The people would benefit from community intergration programmes in addition to the medical rehabilitation programmes.

The country's current challenges include the need to address political stalemate, the economic crisis and one of the world's highest rates of HIV/AIDS infection.

### **1.5 – The Tonga---‘The People of the Great River’**

A look at the name Tonga shows the importance of the river to the people. Moreau, S.J. (1950) offers the meaning of the word ‘Tonga’ as follows; The Tonga were known originally as BaDonga or ‘the people of the river’, mulonga means ‘a river’. In time, the ‘l’ changed to ‘d’ and they became known as the BaDonga, or ‘the people of the great river’. As the ‘d’ and ‘t’ sounds are similar, BaDonga became BaTonga. This researcher asked what the meaning of Zambezi meant and the old men in the villages explained that the river was then called ‘*Kasambabezi*’ and it meant that ‘*It is only those who know (the river) who can bath in it*’. Foreigners were easily preyed on by crocodiles because they did not have the knowledge of the river. In other words, the river belonged to them.

The reason for the chosen area of study, i.e. Binga, is the effects of internal displacement as a particular form of social suffering among the Tonga due to their displacement from the Zambezi valley for the building of the Kariba dam. The effects of this are manifested later in the study.

Binga is one of the most underdeveloped districts in Zimbabwe. It is approximately 12 500 square kilometers of which 9 000 square kilometers is inhabited. It has a population of 300 000. The Tonga are a matrilineal society and account for less than 5% of the national population (the rest of Zimbabwe are patrilineal). Most of the land is under Parks Estates, ie Parks and Wildlife Authority, Safari and Forestry Commission. The whole district is a

malarious area and all the population is affected though other wards are more affected than others. Malaria is a major problematic disease in the district and accounts for 60% total admission for the district (Roll Back Malaria Annual Report 2004-2005). The malaria peak period for the district ranges from the months March to May. After this, breeding sites tend to dry up in most areas.

The district has 21 wards and is served by 11 health facilities. Of the health facilities, 7 are rural health centres, 1 is a mission hospital, 2 are council clinics and 1 is a district hospital. There was a general shortage of staff both nurses and environmental health technicians. Five of the clinics manned by nurse aides are mostly furthest from the district hospital with the exception of one. The district has operated without a medical doctor for the greater part of 2004 and 2005.

It is a settlement of refugee peasant farmers displaced over fifty years ago by Zimbabwe's largest hydro – electric dam, the Kariba. Before 1957, the Tonga used to live in small villages along the Zambezi and around the deltas of the tributaries of the Zambezi river. They cultivated alluvial soils based on recession agriculture, which depended on the flood regime of the river. With this type of agriculture the Tonga could harvest crops twice a year and thus were seldom victims of hunger and famine. Living along the river, water was never of problem for them and they had an easy access to fish.

For generations these families had farmed the broad and gently sloping banks of the river, producing sweet potatoes, corn, bananas, and different types of vegetables. They 'could not remember going hungry' said two old men whom the researcher interviewed during the study. To them, life out there is now recalled as idyllic.

### **1.5.1 - The River Tonga**

In 1955, the River Tonga were visited by the District Commissioner and the Minister of Native affairs of Southern Rhodesia and were informed that they had to move out of the valley to make way for the dam. They were soon to learn that this '*resettlement*' would happen without their agreement.

For many generations the Tonga lived by the fast flowing Zambezi River that in 1957 separated Zambia and Zimbabwe. The Tonga on both sides of the river were very closely related by intermarriage and friendship. The dam, sited at Kariba Gorge flooded the whole of the Zambezi valley upstream of it and compelled the resettlement of the whole population of both north and south banks. On both sides of the river, the Tonga were the losers who faced an arduous journey in the back of open trucks to be resettled in the middle of the bush away from the river. Tremmel, M. (1994) quotes one of the participants in his study as saying; *'More attention was paid to the animals and rescuing them, than to people'*. Some of the participants (old people from the valley) in this study stated that they were left in the open spaces and had to start building from scratch. *'Some people were attacked and killed by wild animals'*. The people from the north and south banks were cut off completely from each other.

### **1.5.2 - Splendid Isolation**

Tremmel (1994) states their life near the river as a time of *'splendid isolation'*. This description needs to be understood in its historical context. He states that the Tonga were basically isolated from the rest of the people of Southern Rhodesia (Zimbabwe) and lived a very traditional life; with the exception of a few men who went for work in the mines or towns. Being isolated had its own advantages such as being free to hunt without colonialist policies. They enjoyed a life of farming the fertile soils as well as catching fish. They were governed by their chiefs instead of the colonial authorities. The absence of government involvement left them free to honour their ancestral spirits and keep their traditions alive.

The Tonga also suffered from their isolation in the sense that the government neglected and left them alone such that there were no schools, clinics or hospitals even as late as 1957 (which was unlike most parts of the country at that time). Infant mortality rates were extremely high partly because there were no vaccinations made available to them. Tremmel says they relied on their traditional medicines for healing illnesses. This was effective for some illnesses but not for some major diseases. They suffered from diseases like malaria, tuberculosis, leprosy, measles etc. As a result, life expectancy was low. It is estimated that 60% - 80% of children died of malaria and diarrhea before the ages of five.

During their occupation of the valley, the Tonga would cross the river to relatives and perform traditional ceremonies in honour of their ancestral spirits (mizimu). The river

connected them to their relatives and friends known as ‘bamutala’, those leaving on the other side of the river. During this study, the researcher also noted how the riverbank dwellers talked fondly about; the river crossings, their love for relatives and the ancestral ceremonies they used to hold together. The river enabled them to remain connected.

### **1.5.3 - Early Years of Resettlement**

Tremmel (1994) states; ‘many described how they lost their sense of unity and togetherness when they were forced to resettle in bushy areas. They built smaller villages and the family homesteads were spread out compared to their kraals situated near the river. There were no more garden produce that supplemented their harvest from the fields. Now under colonial rule, they were not permitted to hunt as before. Lack of rains and the poor soils made the Tonga become dependent on the government for food and years of drought relief. Although there were boreholes and dams in some areas, the water was not enough.

About 23 000 on the Zimbabwean side and 34 000 on the Zambian side were relocated by the Kariba Dam. These figures could be a major underestimate, as they were derived from a census five years before the flooding. Some have suggested the figure of displaced persons could be more than 100 000 (Basilwizi Trust 2004). One group settled on the north side of the Zambezi River (in Zambia) and is known as the Plateau Tonga. The other group settled on the Zimbabwean side. These two groups are related and both governments still recognize the ties. They are required to use passes to cross the border to visit relatives rather than using a passport like everyone else. The researcher noted from their stories that theirs was a ‘riches to rags’ story’ for they are unbelievably poor; they blame their poverty on the forced resettlement onto the dry mainland.

During the first two years of resettlement, the government provided food relief of grain, powdered milk and salt. The government also built the Binga district hospital, some schools, sinking boreholes, small dams and constructed roads.

It is however sad to note that all this is now history. From having plentiful food as well as a good social life, the Tonga are now on the verge of starvation and have to beg or borrow in order to survive. The researcher noted how they are now scattered looking for survival means like fertile fields and wild animals (mountains) for food. With the present socioeconomic and

political situation, their predicament seems to have worsened. Scudder, T. who has noticed a pattern that has emerged from most large dam constructions, points out that much attention is given to the technical construction of major dams while the resettlement programmes for the people are initiated without much ample consideration and research. In the case of the Kariba Dam construction, the people were moved before the settlement areas could support them. He maintains that *'compulsory and fast resettlement forces its victims to undergo extreme psychological, physiological and social – cultural stress, as well as inadequate water supplies'*.

This situation is similar to the images used by the 'water refugees' of Haiti studied by Farmer, P. (1992). He quotes the peasants as saying, *'Everyone lost half of his life. Even a tiny bit of land, no more than this courtyard, would yield more than you could eat. You could never harvest all your rice; there was so much of it'*. One old man said he grew old quickly because of the suffering. The old men's reminiscence was that of the large number of animals they possessed; cattle, goats and pigs of which they have nothing to show for. Now, they talk of not being able to look after their families. They talk of planting and not harvesting the crop due to lack of rains and the infertile soil. One Haitian was quoted as saying, *'That wasn't land we had. It was a Christ, and it's now under water---leaving the valley brought nothing but pain for me'*. The researcher found a lot of similarities between the 'water refugees' of Haiti and the Tonga (which the researcher can call 'water refugees' as well since they too were displaced from the Zambezi valley). Often, the contrast is placed in stark terms of before and after.

Simple survival is becoming increasingly difficult. Therefore it was extremely difficult to be carrying out my fieldwork at that time. The BaTonga had very little food if any. The mountain communities are less fortunate than their counterparts in the lowlands because according to them, they reap half of what they cultivate and the other half is eaten by elephants and other animals and birds. Later the elephants follow the villagers to their homesteads at night and bulldoze the granaries and eat the food that was expected to last for the next few months. After this, they have to buy or beg from relatives until the next harvest season.



## 1.6 - The Tonga

The climate does not support both commercial and subsistence crop farming, but wildlife management. This is so because the district is characterized by poor soils and very hot weather. Temperatures can get up to 42C. Their economy is based on small scale fishing as well as tourism. The lake shore is state owned and the government restricted access to the lake to a few fishing camps. It is therefore not surprising that the households in the resettlement areas suffer from some of the highest levels of unemployment and poverty in Zimbabwe (Basilwizi Trust 2004). Tourism has of late declined due to the country's political situation. All areas are endemic to malaria and the situation has worsened due to fuel shortages in the country leading to poor malaria control programmes.

In her studies of the Tonga; Colson, E. (1967) notes that every Tonga is a member of some clan and the clans are the most enduring units in the society. The clans are named, dispersed, exogamous units in which membership is derived through matrilineal descent.. It is Tonga dogma that the matrilineal group is not internally differentiated into segments based on a common descent from one woman. It is the mother's brother who holds the superior position in a family. He must be treated with respect, and has the right to offer advice to both his sister's sons and daughters. He has a voice in arranging the marriage of his sister's daughter and receives a portion of her bride wealth.

To the Tonga, the true adult is a person who is married and holds a ranking position within a household based on this marriage. As such, however, it is a goal within the reach of all. The researcher noted this by way of observation and talking to both men and women in the villages. The disabled women I noted were not married but had children, e.g. Peter's disabled aunt; and stayed at their family homesteads. One blind man, a parent to one of the disabled children was married to two wives. I gathered from the research assistant that such marriages are arranged in most cases by the families. The single people encountered were very old widows; otherwise most of the population were married or remarried.

Polygamy is allowed and found among men of all ages save for the very youngest. This researcher noted that homesteads could have as many as twenty five or more children. Marriage is looked upon as the inevitable portion of every man and woman. Colson, E. (1967) states that children are necessary to the routine work of the household, since many tasks are

delegated to them. Therefore, a succession of children is necessary if the household is to maintain its independence of others for any long period of time.

Thus, the study was conducted among Zimbabwe's poorest population in the middle of the dry season. It is a setting of near total illiteracy. Some of the problems encountered by the researcher were poverty, lack of support, lack of knowledge, lack of education, lack of health facilities and access, and lack of resources. In this case, disability and social effects will be examined in the light of past misfortunes as the study later reveals

### **1.7 - 'Go – the water will follow'**

These are words from two old men who were evicted from the fertile valley where they and their forefathers had lived for generations. The researcher could detect mist in their eyes as they said the above words. *'We had a good life. The soil was fertile and we had more water than we needed. We grew corn, sweet potatoes, bananas, vegetables and other crops – life in Kasambabezi (Zambezi valley) was good'*. These were words of two old men interviewed by the researcher. These two were newly married and in their early twenties when they were forced to evacuate the valley. Apparently, their elders asked the 'white man' how they were going to survive on the dry land and that is when they were told to continue moving inland and that the water would follow them. Up to the present day, even the young Tonga make a joke of *'the water following them'*. Sadly, the water did not follow them. The Tonga suffer from persistent droughts but the government has not brought piped water to the villages.

Another example is that of Tremmel, M. (1994) who says that although there were some boreholes and dams in some areas, the Tonga complained that sufficient water was no longer available to them, like it was along the Zambezi. During the gatherings, one of the women, Simpongo Munsaka, kept repeating over and over again, 'We left with our property and our bodies, but we left our water behind. We would like our water to follow us. They promised that the water would follow us'.

This continues to be a major problem for the women. As one drives along, it is a common site to see the women carrying large containers of water on their heads as well as on their backs like a baby so as to have enough water for the day. Worse still are mothers with children with

disabilities who often have to carry this huge bucket as well as a baby on their backs. These distances can be as long as a two hours journey. The researcher had the privilege of accompanying a group to the nearest borehole which was two hours away. On getting back to the homestead, my chest felt hot and tight and I coughed a lot. I felt muscles in my body that I had never felt before. It was tough. I noticed that it was not easy for the women either although they were used to it.

The drop in water supplies in dams and rivers also affects the quality of water; and this can lead to cholera outbreaks. On record is the cholera outbreak of 2003-2004, which claimed several lives in Chunga ward. In Furunga, the villagers were using salty water for household purposes, ie drinking, cooking and washing. The researcher commented on the children's yellow corroded teeth and was told that this was caused by the water. The women stated that they do not use salt when cooking vegetables or any food that needs salt added to the food. The salt in the water was enough. I took a sip, quickly swallowed the water and returned the cup to the women. I also gathered that the water discolours white clothes.

As if to add salt to their injuries, the government now has plans to transport water from the Zambezi to Bulawayo, to '*the people of the city*', a distance of about 450 kilometers away. The Tonga state that '*Our land was taken away so that they could have electricity, and now, this*'. The old men talk of the dehumanizing effect this has had on them as a people.

### **1.8 - Social Suffering and Poverty**

Definition of Social Suffering ; Benatar, S. R. (1997) states that '*the term social suffering describes collective and individual human suffering associated with life conditions shaped by powerful social forces*'. He continues to say that unlike physical suffering or mental illness, it is largely unrecorded. New measures such as disability adjusted life years, designed to document the global distribution of morbidity in economic and individualistic terms, only barely represent a much more complex concept of suffering as a social experience and neglect most of what is at stake for people globally.

Social suffering is the result of what political, economic and institutional power does to people, and reciprocally, from how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that are usually

divided among separate fields: health, welfare, legal, moral and religious issues. They destabilize established categories (poverty, war, torture etc.). Social suffering is at the same time about collective and individual (Kleinman, Daas, Lock 2006).

Structural violence is the negative impact – beyond their own control – of social structures (political, religious, cultural etc) on the lives of individuals and groups. ‘Social suffering’ and ‘structural violence’ bring in a new perspective in that it takes politics\power down to the household and individual level. In the case of the Tonga, politics has resulted in them starving due to government withholding food from the people. As seen before, NGOs have been banned from entering the district to distribute food to the people.

Farmer, P. (1992) gives a good example of social suffering in Haiti; (see the following chapter) in the case of Anita; a poor village girl who leaves the village to seek employment in town. Later she is seen going back to the village to ‘*die – a decent death*’ after contracting AIDS. As stated before, this researcher witnessed similar cases in Binga among the Tonga. Due to poverty and lack of resources, young people were leaving the villages in search of work in nearby towns and cities. Whilst working out there, they contract HIV\AIDS and are seen to come home so as to be taken care of by parents or relatives until they die. In such cases, Farmer and Kleinman see the idea of personal accountability as less powerful and so blaming the victim is not right. It is a case of where individual rights are often underemphasized and also frequently unprotected. The Haitians, according to Farmer, (1992) blamed their problems on historical exigency, unjust social structures and North American racism. The Tonga on the other hand blame the government for their ‘*forced displacement*’ from the Zambezi valley which has caused their suffering.

They remember old people, children and the disabled getting sick and dying from lack of food and the diseases of the mainland. Some died of grief. Uprooted from their land, they left behind a way of life and a culture that was built around their closeness to the river.

McDowell, C. (2005) states that displacement disproportionately affects the poor, those who are distanced from the centres of power, who often live outside the formal economic system, are members of minority populations speaking a different language to the dominant national language, and who generally do not fit a metropolitan national identity. The Tonga are seen to fit the above description.

At the time of research, the area had not had good rains for the past four years, a common feature for the whole of Zimbabwe. This has led to severe food shortages since 2001. This, as well as the barring of international relief agencies from feeding the hungry, has worsened the situation of the Tonga. At the time of the research, the government had stopped non – governmental organizations (herein referred to as NGO's) from participating in the distribution of food aid in fear of NGO's use of the exercise as a pretext to mobilize support for the opposition party. As one government minister (Didymus Mutasa) stated; in the article; **No food before elections – Mugabe;** said, *'Most of these NGO's play politics with food and they might as well use the food handouts to influence our people to vote for the imperial lapdogs, the MDC. We are busy with the Senate elections and after that we will look at the situation. But it should not be lost that we have the capacity to feed our own people'*. (Article from The Zimbabwean Print Media: 14 – 20 October 2005).

In Binga, food aid had been stopped since 2004 before the parliamentary elections. The researcher found the same problems during her fieldwork when she was purchasing maize meal for the participants she stayed with at their homesteads. Most people have no access to food because there are virtually no maize supplies from the Grain Marketing Board. Being a dry area, supporting the opposition as well as other factors, the Tonga are considered worse off than the rest of the country. They see themselves as a 'forgotten people' both by the previous Rhodesian and the current Zimbabwean governments.

Poverty, as witnessed by the researcher is the major factor within the Tonga communities. This has direct implications on village life because one's basic needs are not met. This resulted in the researcher finding that the villagers major expectations were mainly basic needs of food and clothing. The food deficit results from drought, economic and political problems. Poverty, in this case as experienced by the researcher can be put down as a form of capability deprivation. I understood poverty as a type of powerlessness, not only the relative lack of food, shelter, material goods and amenities compared to other people or societies, but also the inability to affect the situation. What it amounts to in the last instance is being denied human rights, in the most basic sense.

In Binga, I came across a '*defeated*' people; people who were not capable of helping themselves anymore. What does one do when the one thing that you had left has just been

destroyed by elephants? This had just taken place in the village of Dumbwe that I had visited where the villager's gardens had been destroyed by elephants the night before. The animals had eaten all the vegetables. This was going to be food for the next few weeks before the river dried out. I looked at the child with disabilities who was already malnourished, and wondered what would become of him in the next few days, weeks or maybe months if he was lucky.

Action Contre la Faim (Action against Hunger) (France) writes....*Yet hunger and malnutrition are by no means dictated by fate or a curse of nature; they are man made. To die of hunger is equivalent to being murdered: while chronic and serious under nourishment and persistent hunger are violations of the fundamental right of life....*

It is an affront to human dignity to see how many people starve to death or die from hunger related illnesses.

During visits to the different homesteads and carrying out in-depth interviews and participant observations, the researcher noted the gross lack of food within the community. It was easy to note the malnourished children, and worse were those with disabilities for they were getting infections as well. The mothers lamented the nutritious porridge that the children used to get when the government used to send it to a central point in the villages. This had been stopped due to fuel shortages. The porridge was not being delivered to the intended beneficiaries.

As a result the researcher asked for permission to carry a load of children's porridge to the different sites where the women gather to cook the porridge and feed the children between the ages of one to five years. This was done if the sites were on our way to the destination of the project.

The exercise proved to be a success judging by the smiles on the mothers faces as well as the full – bellied toddlers. Sadly, the researcher could not continue with the exercise due to political reasons cited by the 'office'. I later discovered that I was not to be left to take up duties that were meant to be someone else's (I could be campaigning for the Opposition). So, that was the end of my Samaritan work. I was bitter to say the least. *How could anyone have a right to stop someone from getting food?* This is really equivalent of murdering another fellow human being because these children were going to die from hunger related illnesses.

The incident shows that it is indisputable that hunger and famine are largely a result of drought. In Africa and the third world, however there is an evident correlation between hunger and politics. The present hunger crisis in Zimbabwe is due to a combination of factors, which are, erratic rainfalls, a rapid declining economy and the impact of the government's land reform programme. To make matters worse it is alleged that the government uses food as a political weapon. Food is reportedly used to buy support and maize meal is mainly distributed to those who possess the ruling party's membership card. It is a well known fact that the Tonga support the opposition and hence their predicament. One may think that they are foolish to do this but they may have their own reasons for that. My conclusion to the matter of food and politics is that starving a nation for political gain is a crime against humanity.

Starvation today mainly occurs when a nation is disrupted by wars or political/economic crises in some ways, as the case of Zimbabwe. (Ethiopia is another good example). A nation does not have to starve if drought alone is the cause of famine. An example is Botswana, Zimbabwe's neighbouring country which is usually hit by the same draught periods but one does not see famine in the same way. This is because a well functioning draught-relief programme is in place. In the case of Zimbabwe, the European Commission has continued to provide the Zimbabwean population with food and other humanitarian aid exclusively through international and non- governmental structures. However, these food aid efforts are hampered by politicization.

The case of the Tonga leads one to think that the ruling party has an indirect intention to starve a part of the nation. Evidence of recklessness on the part of the government of Zimbabwe can be deduced from some statements like Didymus Mutasa's '*We would be better off with only six million people, with our own people who support the liberation struggle. We don't want all these extra people*'. (ZANU – PF Organizing Secretary, 10 August 2002).

The researcher remembers getting to Binga and chatting to the nurse in charge of the expanded programme on immunization (EPI). During that time, the nurse was going out to the villages twice a week to give out vaccines to the children. This took place because the nurse's husband was transporting her and other nurses using his own fuel. The government had no fuel to provide the hospital for that purpose. After two weeks, the husband and wife team was stopped from carrying out the work. It was said that they were campaigning for the

Opposition. One wonders what happened to those poor children who were denied the vaccinations.

In Binga, malnutrition now affects most of the children below five years of age as well as a certain proportion of the adult population. The researcher remembers coming across an old lady lying on the side of the road because she was too weak to continue walking home. Apparently, she had not eaten since the day before. On another occasion, we met two sisters walking in the 42 degree heat trying to sell two chickens so they could afford to take their sick baby to the hospital. This was a two year old disabled child who was supposed to be the first child I had to see. They had walked for miles. The baby was so dehydrated and malnourished that we had to take the mother and child to the hospital on our way back.

Malnutrition, lack of food as well as lack of vaccines was a sure way of death to the children especially the disabled children who were sickly. The research assistant tried to give the above baby a milky drink that she had. The baby found it very difficult to swallow. It was so emaciated such that it did not look like it had any energy left to swallow the drink. The mother reported that the baby had not taken any food for three days and was so weak that they decided to walk along the main road so as to sell the chickens to passers by and take the child to Binga hospital. This was my first day in the field and the research assistant told me to brace myself for such incidences for they were a common occurrence.

Another common site was of cows dying by the road sides due to lack of food and water. This has resulted in the Tonga having few or no cows left at all. The hungry cows would disturb us at night as we slept out in the courtyard. They would be coming to eat the grass on the newly thatched huts. We would get up and chase them away. This could happen several times during the night depriving us of sleep. The animals that are seen most frequently scattered around the villages are the drought resistant goats. Still, many families have no goats left because they have exchanged them for food or sold them for other purposes. In the mountains, these are often attacked by lions.

*'We were not threatened by elephants before, but now they are everywhere,'* says the seventy year old traditional healer from Siyabuwa village in the Zambezi valley. (allAfrica.com;-02-09-06). With drought persisting, the number of deaths may increase still more as elephants and humans compete for resources. Current conditions have also taken a severe toll on the



animals: over a hundred elephants died last year-something blamed on serious shortages of water and grazing. The authorities say the country's fuel shortages are affecting the way they run the park – for example they are struggling to purchase and deliver spare parts for the water pumps. Severe food shortages together with a deepening economic crisis have left millions of Zimbabweans in a desperate situation – now it seems their plight is being shared by the animal population too. This is a consequence of the present economic\ political policies.

(all Africa.com; - 02-09-06) ; Sachikonye Lunga's face twists at the mere mention of the word 'elephant', which doubtless evokes memories of his eldest son being trampled to death last year by one of the animals. *'We no longer bang empty tins to scare elephants away lest we anger them, but just watch as they descend on our fields and graze on our crops'*. The researcher was at Siyabuwa village and the villagers narrated sad stories about the destructions caused by elephants to both human beings and their livelihoods like fields and gardens. This takes place during the dry season when artificial wells break down and pools dry out in the wild park areas. This results in wild animals moving out to the hills where the mountains are, as well as the villages in search of food and water. During this process, civilians including school children are killed on their way to or from school.

On the other hand, civilians are killed by elephants when venturing into the mountains in search for food. Poaching has also become a common activity since villagers have to survive. The villagers kill the wild animals and dry the meat on huge trees in the bush until it is dry. Days later they collect the dried meat (biltong) and take it home to their families. I gathered from the villagers that this carries a prison sentence but still does not deter them from killing the wild animals. *'We have to survive'* they stated.

Displacement from the valley has also resulted in women and girls in Binga being hardest hit by the Aids pandemic. Most of the women and girls are socially and economically disadvantaged and, with the onset of Aids, women are infected and often widowed, and children are orphaned. It is a common phenomenon for Tonga women to marry early in their teens, for example from twelve years of age, as a survival strategy. Some of the participants attributed this to *'my mother had died, poverty at home, and that they were hungry'*. In most cases this led to marriages to older men who already had other wives.

Poverty has also seen the migration of young women to towns to seek employment and in the process, get infected with the HIV virus. When this happens, it is sad to see them coming back to the villages to die for they cannot afford the treatment from the hospitals, let alone the anti-retro viral drugs. This is seen to resemble the case of Anita (Farmer P. – Haiti case) whereby she goes back to the village to die a decent death.

It was common to see an old lady looking after her son or daughter dying from Aids (home based care). One old woman mentioned that in the end, her son died from hunger. This must have been painful for she still felt that if she had enough food, her son would not have died that soon. One could see that she was blaming herself for the death. The pandemic has resulted in many grandmothers looking after their grandchildren (orphaned). This has resulted in one of the biggest challenges that communities in Binga district are facing today which is supporting the huge and growing number of orphans and vulnerable children. This is social suffering at its best.

It is sad to note that to this day, the Tonga still have not benefited from the electricity or the water from the Zambezi. To date no compensation has been paid out to the families. Only one mission clinic and the district hospital have electricity. The researcher came across a clinic that was closed down due to lack of water. It is a common phenomenon to see Tonga women walking for long distances carrying buckets of water for household use. They walk long distances to the fields with babies on their backs, and still have to cultivate the land when they get to the fields. They have to climb trees in order to get wild okra leaves and ‘busika’ to feed their families. Life gets much more difficult for a mother with a child with disabilities who needs to be carried on her back all the time. This is the child who is sick most of the time and needs constant attention from a weary and worn out mother.

These are some of the results of social mobilization or displacement of a people by a government. The Tonga are still experiencing problems of poverty fifty years after the displacement. The government should have put something in place before moving them, and the present government should have continued supporting them to enable them to cope. *‘If there had been no dam, we would not be suffering like this’* said one old man interviewed by the researcher. Life for the Tonga today is abject misery.

### 1.8.1 - Comparison with Haiti

Feilden et al. (1981:1) quotes a situation similar to that of the Tonga among the Haitians. Haitians have low levels of literacy, and little paid employment. This results in women taking up prostitution so as to survive despite the HIV/AIDS pandemic. Young people go to the nearest towns to look for jobs. Most of them get low paying jobs because they have little or no education. This results in them staying in the poorer parts of town where prostitution and other illicit activities take place. Like Haiti, these young people end up as Aids sufferers.

The researcher witnessed a large number of grandmothers (old ladies) who were looking after their daughters in their last stages of illness from HIV \AIDS. Some of them had come back from the towns where they had worked as house servants. According to the villagers, the reason for the illness was bewitchment by fellow villagers or jealous colleagues at work in the towns. Only a few people admitted to AIDS causing the illness. The researcher remembers a sick young woman left outside in the shade whilst we went to the gardens. On coming back, she was hallucinating and asking why we were late. When the mother asked her why she was asking, she replied, *'You could have found me dead for there were cows here and they stamped all over my body'*. On taking a closer look, the mother noticed that it was chickens that had walked over her. She wiped a tear, shook her head and stated that she has to live with that every day.

It is a well known fact that most grandmothers in rural Zimbabwe do look after their grandchildren whilst the children's mothers go to work in the cities. These mothers then send some money back home for the children's care (when they can afford it). This also includes disabled children. With the AIDS pandemic, grandmothers are seen to be taking care of both people, i.e. grandchildren as well as AIDS sufferers. Such a situation puts a disabled child at a disadvantage because they may not get all the care they need from an overworked grandmother who is also financially disabled. In this case, the poor grandmother is the one that has to suffer if and when treatment decisions may have to be made. Coping with care of the disabled child becomes increasingly difficult in such circumstances.

In Binga, mothers are no longer able to send children to school because they cannot afford the fees. The Tonga have been known not to send children to school for several reasons such as the long distances children have to walk to get to school, or the parents have no food to give

the children to take to school. The few that were attending were not going any more because the parents stated that they could not afford the fees. In one village, the researcher remembers having to pay the term's school fees for three young girls so that they could be given their examination results. The mothers stated that the girls were not going to continue with their education due to financial constraints in the family.

Education (discussed in literature review) was noted to be more or less for the privileged few. In such cases especially in developing countries, disabled children are the ones that are not sent to school compared to their siblings that are not disabled. This takes place when a choice has to be made for example due to financial constraints within the family. In the case of this study, all the children suffered from cerebral palsy and so they had mobility problems, different degrees of learning disability and other problems. This would make them less liable to get an education in such an environment. The other major problem for them was that there was no '*special school*' in the district. One may therefore conclude that most of these children will not have an education at all. These will be the poor citizens of tomorrow; and not of their own choice.

Sick children as well as adults cannot manage the hospital fees so they stay at home and (hope for the best or die). The researcher witnessed on several occasions the death of young pregnant women who died during labour because the district hospital had no doctor. This situation obviously increased the birth of disabled children due to prolonged labour or lack of expertise by the birth attendants at the clinics. The other problem was that of lack of fuel to ferry these women to the nearest hospital with trained personnel. The villagers explained that even if there had been a doctor at the hospital, they still could not afford to go because they could not afford the hospital fees. Most people still use the traditional healer but these are getting to be very expensive, according to the participants. The '*Zimbabwean Herald – newspaper*' (12-01-06) states that more than 80% of people in Zimbabwe consult traditional practitioners. Some people are now turning to spiritual healers and the '*new churches*'. This has created an environment which is increasingly pluralistic in its health care delivery systems; the same as the Haitian situation.

This unfortunately puts the child with disabilities at a disadvantage for it needs medical attention as well as rehabilitation. The researcher noted razor marks on the bodies of the disabled children who had been taken to the traditional healer for treatment. When asked

whether or not the treatment had worked, some said that it had helped a little, and some said it had not. During focus group discussions, the mothers said if they had the money, they would try all the treatments there were in order for the child to get treated. From the researcher's observation, as well as talking to health professionals and medical notes at Binga District hospital, 50% of the deaths are among children under the age of five years; with nearly 75% of deaths associated with or caused by malnutrition. Infectious diseases account for the majority of deaths. The major causes of childhood deaths are diarrhea, pneumonia and tetanus.

The Tonga, like the Haitians, felt that their governments had let them down. They were flooded out for the benefits of electricity which the '*big shots and the city people*' enjoy. They still find themselves in the darkness. '*But if they were to let loose these waters*'--- is the wish of these displaced people. For both groups, food production is affected from time to time by droughts and infertile land. They have to beg or borrow in order to survive if they do not have the money. Farmer, (1992) states that poverty is the central fact of life for most rural Haitians. To live in a village is to witness the struggles of the poor as they confront the deepening economic crisis that currently grips them. The researcher, having lived with the Tonga for four months, witnessed a similar situation.

### **1.9 - Consequences of Poverty for People with Disabilities**

Eide, A.H. et al (2000-2003) state, '*A large majority of people with disabilities live in developing or low income countries, very often living without optimal technical, medical or social support that could have improved their level of living conditions considerably. Disabled people are often marginalized and belong to the poorest segments of society*'.

DFID (2000e) '*Poverty is not simply the consequences of a lack of resources. Some people are unable to access existing resources because of who they are what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty*'. This is exclusion from social, economic and political life. Maxwell. S. (1998) writes that exclusion leads to lack of resources, lower expectations, poor health and poor education. Yeo, R. (2001) states that not only do disabled people experience disproportionately high rates of poverty, but being poor dramatically increases the likelihood of getting an impairment, for example due to the

hazardous nature of the job. Those living in chronic poverty often have limited access to land, healthcare, healthy food, shelter, education and employment.

The situation of the Tonga is that of chronic poverty, meaning that it is ever present and never ceases and has been passed from one generation to the next. Chronic poverty and disability are inextricably linked. In other words, disability feeds on poverty, and poverty on disability. Other researchers see the relationship between disability and poverty as a vicious circle. Lwanga – Ntale, C. (2003) states that it is a fact that in developing countries, disabled people are ‘born into poverty’ and that both poverty and disability are mutually reinforcing. Because of poverty, many people become disabled; and that disabled people have very limited access to health care and facilities (including immunization); they have very rudimentary feeding and nutrition; they are exposed to a number of disabling conditions. Lee, H. (1999) states the solution to this problem as; ‘*Because disability and poverty are inextricably linked, poverty can never be eradicated until people with disabilities enjoy equal rights with non – disabled people*’.

Ashton, B. (1999) states that the birth of a disabled child is a tragedy. Where there are limited resources it may be seen as economically irresponsible to give an equal share of resources to a disabled child who is perceived as unlikely to be able to provide for the family in the future. ‘*Early lack of investment in a child with disabilities is not just a reflection of ignorance. In situations of poverty this is a desperate but rational decision*’. She also notes that children with disabilities often get last access to food and other basic resources. When they get ill, they are often not given treatment but left to the ‘*hand of God*’. She further states that they are less likely to be sent to school for fear that they will not cope; or that their disclosure will stigmatise the family and affect the marriage prospects of siblings. Many of these children turn to begging as a profession and in some cases become street children.

Scheper- Hughes, N. (1992) explored maternal beliefs, sentiments, and practices bearing on child treatment and child survival among rural migrant women of Alto do Cruzeiro of Brazil. Her research findings run counter to biosocial evolutionary analyses of the universality of ‘*mother love*’. They challenge universal, biologically based gender roles, instead emphasizing the importance of culture and political-economic context in explaining human behaviour. It is the poverty and hopelessness of the situation that leads mothers to ‘*desperate but rational*’ decisions; Scheper-Hughes argues that high child mortality in the developing world is the

result of political economy, and not medical technology. Finally, she argues that maternal thinking and practices are socially produced; rather than universal emotions or maternal sentiments.

In 1992, Zimbabwe introduced some form of legislation against disability discrimination. CBR programmes were introduced in most districts in the country but this is still on disability prevention, rehabilitation and individual support rather than on anti – discrimination and rights based legislation. The government has to recognize the importance of inclusion so that disabled people will not be an economic burden on the rest of the population. In Zimbabwe, less than 1% of disabled people are thought to actively contribute to the economy (Lee, H. 1999).

### **Reflections on Chapter – 1:**

Haiti is the parish of the poor. In Haiti, it is not enough to heal wounds, for every day another wound opens up. It is not enough to give the poor food for one day, to buy them antibiotics for one day, to teach them to read a few sentences or to write a few words. Hypocrisy. The next day they will be starving again, feverish again, and they will never be able to buy the books that hold the words that might deliver them. (Aristide 1990; 67) The above paragraph echoes the plight of the Tonga.

The suffering of both the Tonga and the Haitians seem to demand that we understand their current suffering in the light of past afflictions and current poverty. Farmer, P. (1992) states that some such as ‘Anita’, have exposed for us the mechanisms by which they have been ‘*put at risk*’ for exposure to HIV. Others have explicitly linked contemporary travails to the oppression and struggle that have long been the heritage of the Haitian poor. The same explanation can be attributed to the situation of the Tonga today. Their suffering fits neatly into a political and economic crisis. Individual blame and accusation has no place in their suffering.

Basilwizi Trust is an NGO in Zimbabwe committed to building the capacity of the people affected by Kariba Dam to help them change the conditions under which they live. Basilwizi Trust believes that the people affected should take the lead in the advocacy process and Basilwizi should act as facilitator for empowering the people through training in advocacy

and lobby skills, negotiation skills and conflict management skills which are the success of the reparation issue.<sup>1</sup>

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<sup>1</sup> The researcher found the following organization and its work as follows;



## 2.0 - Literature Review

The International Year of Disabled Persons in 1981, followed by the United Nations Decade for Disabled Persons declared by the United Nations in 1983, put disability into a global context and posed the question of how disability may be understood in a multicultural world. How are deficits of the body and mind understood and dealt with in different societies? How is an individual's culturally defined identity as a person affected by disability? What processes of cultural change and shape local perceptions of disability? These are some of the questions that will be posed by this study in order to find out the perspectives of the parents with children with disabilities and their coping mechanisms.

The first estimates on the prevalence of disabilities by the World Health Organisation were that 10% of any population was disabled. Later these figures were modified to 6 or 7 percent, giving a global estimate of 245 million disabled people (Helander, E. 1993). Estimates depend on what counts as disability (the first figures included malnutrition), on how severe an impairment must be before it is considered disabling, and how categories are implemented in actually gathering data. Renker, (1982) claims that one out of ten children in developing countries are born with or acquire physical, mental or sensory impairments that interfere with their capacities for normal behaviour. Aide, A. et al. (2003) study on 'Living conditions among people with activity limitations in Zimbabwe' carried out a representative regional survey and found a total of 2.9% disabled people in Zimbabwe, using concepts outlined in the International Classification of Function, Disability and Health (ICF).

In studies of how families cope with the care of a disabled family member, culture has been both a neglected and misused variable (Ingstad, B. 1988). Culture has largely been neglected in scientific studies from the industrialised world. This has for instance, led to theories of crisis and coping behaviour postulating more or less universal patterns of reactions with no reservations made about possible cultural diversities (Caplan, 1981; Cullberg, 1966; 1979). Despite a growing awareness of the importance of culture among professionals working with immigrant families, this is still the case. On the other hand, too much emphasis on culture can lead to 'victim blaming' of the family taking care of the disabled child; as (Grunewald and Jonson, 1981) state; *'descriptions of the life conditions of disabled persons and their families in developing countries often tend to see cultural beliefs as the main variable influencing*

*attitudes and behaviour, leading to patterns of hiding, neglect etc. of disabled persons*'. This has been noted in cases where a family is blamed for '*neglecting or abusing*' a disabled person in the home, without looking at other possible variables for the cause of the so called '*neglect*'. As a result, this study will have culture as one of the variables of coping with disabilities.

Most research on mothers with disabled children has interpreted maternal behaviours and feelings in negative or psychopathological terms (McKeever, P. and Miller, K. 2004). Not many researchers have looked into the logic of mothers' practices. In the case of Zimbabwean women in the rural areas, a case of child neglect could be due to labour migration whereby men leave to seek employment in town. This can be seen in the case where the mother leaves the child when she has to carry out household chores like fetching water or firewood. In such a case, if the husband was at home, he would have stayed and looked after the disabled child whilst his wife fetched water and firewood. The practice of leaving the child alone '*outside*' (kitchen door locked) can be interpreted as neglect; whereas the mother locks the kitchen door to prevent the child from getting in and maybe end up falling in a fire or bucket of water; in other words, she is protecting the child.

Research needs to go further and ascertain these actions before coming to a general conclusion. As an Occupational Therapist I find that I too am caught up in this issue of interpreting maternal behaviours and feelings. As a professional, one finds that one gets good at giving out instructions, aids and advice based solely on the clinical setting and with little regard to the client's culture, social, economic and political situations. It is important now that these perspectives be incorporated as essential dimensions to exploring their own as well as their children's needs and experiences.

To this researcher's knowledge, no study of this nature has been carried out previously in Zimbabwe. It is my intention that this study will inform other researchers on the importance of gathering such information which is useful and can be used as a pilot study for larger studies in the future.

## 2.1 - Disability and Cultural Beliefs

Keesing, R. (1981) states that culture refers to learned, accumulated experience. A culture therefore refers to those socially transmitted patterns for behaviour characteristic of a particular social group. Goodenough, (1961; 521) states culture as the organized system of knowledge and belief whereby a people structure their experience and perceptions, formulate acts, and choose between alternatives. This sense of culture refers to the realm of ideas. Whyte, S.R. (1989) states that culture is seen at the least as a form of logic, a set of interrelated categories, if not as an elegant symbolic system. Society might have its oppositions and conflict, but it certainly has a clear structure, which is brought into play in response to misfortune.

In every society, there exist beliefs about sickness and health care and disability. Talle, A. (1988) states that *'beliefs are common and shared cultural knowledge and are embedded in the cognitive structure of the society'*. It has been noted that people usually have their own specific understanding of the cause and development of a disease case that draws partly on the repertoire of general beliefs but also on situational factors of social, economic and political nature. However it has been noted that there is a lack of agreement between a shared general belief system and the diagnosis of an individual case done by the relatives or health practitioner. This has led Arthur Kleinman (1980) to make the distinction between illness (patients' perspectives) and disease (healers' \ doctors' perspectives).

Talle (1988) states that in order to understand the concept of disease (disability) one needs to look at cultural beliefs as well as a contextual analysis in order to grasp the phenomenon in its full social and cultural setting. He gives an example of how the Maasai (Kenya) perceive disease as a sign of social or cosmic disorder projected on the human body. Therefore the most effective prevention against diseases and other misfortunes is to care for and manage social and divine relations properly. Hence moral misconduct and transgression of normative rules may easily lead to disasters like incurable diseases. This study will therefore try to understand the concept of disability by looking at Tonga cultural beliefs as well as the social setting.

The notion of beliefs is taken further by the fact that e.g. in disability studies, it is necessary to make a distinction between what we believe and what we actually know. An example is the

*'supposed poor quality of life for people with disabilities in developing countries'*; as well as Ingstad's (1988) *'the myth of the hidden disabled'*. The latter has the assumption that disabled people are hidden away. This shows us that as researchers, we should be careful not to blend beliefs and actual knowledge and turning them into facts.

## **2.2 - The Concept of Attitudes**

In trying to understand what we mean by attitudes towards disabled people, one finds that the concept is often used without any definition or clarification. It seems to imply a mixture between belief about the origin of disability, what people say that other people think or do, and what they think themselves. Rarely are studies of actual behaviour combined with survey questions and the social setting in which such behaviour takes place is hardly ever examined. Studies have been noted to have similar conclusions like; disabled people are stigmatised and so on, when the above is not taken into consideration. It is therefore worth noting that attitudes may vary with the social situation in which they are acted upon. They are also socially as well as culturally constructed and dynamic in character.

### **2.2.1 - Beliefs and Attitudes**

In societies where the so called personalistic (*see footnote*) medical systems (Foster 1976) play an important role, the connection between belief and attitudes may be more direct, but seldom as strong as the myth tends to indicate (e.g. Ingstad's *'myth of the hidden disabled'*). If a particular type of impairment is believed to originate in the parents breaking an important taboo, this may lead to shame and reluctance to exhibit their misfortune in public. However, most such medical systems seem to have inbuilt a flexibility that makes it possible to construct alternative explanatory models that lessen or remove completely the stigma attached to an unfavourable *'diagnosis'*. This is because it is the believed origin of the condition, and not the symptoms and their physical cause as such, which is seen as most important (Foster 1976). Thus similar symptoms may have different origins, and the same origin of misfortune may cause very different symptoms.

### **2.2.2 - The relationship between social position and attitudes**

This is shown by Helander, B. (1990: 41 – 44); He cites that disabled people with similar impairments are treated differently within the same community if there are differences in the social position of the disabled persons and their families. Low status or bad reputation may spread to the disabled person. There is also the notion of ‘courtesy stigma’ Erving Goffman (1963; 30) whereby a disabled person in a family may influence the way the whole family is looked upon by others.

### **2.2.3 - The relationship between life experiences, emotions and attitudes**

Previous life experiences are another important source of influence on people’s attitudes and behaviour toward disabled persons. In the study of families with disabled children in Norway, (Ingstad 1988 and Sommerschild 1984) found that previous positive experiences in handling other types of crises became a source from which parents could draw when they got a disabled child. They identified two types of reactions to the experience of learning that their child was disabled; those who said that they got a terrible ‘*shock*’ which it took them sometime to overcome, and those who saw it as ‘*just one of those things that happens in life*’.

### **2.2.4 - The relationship between attitudes and behaviour**

As noted before, attitude is not necessarily a readiness to act, and not necessarily the same as action nor does it determine action or behaviour. In order to understand how families cope with the care of a disabled child, how disabled people cope with their life situation, and how people relate to disabled friends and relatives, we must take living people as our starting point. To get a true picture we have to analyze actual life situations and identify the constraints and possibilities, beliefs and values that generate patterns of coping with disability (Ingstad 1991).

**In conclusion**, the concept of attitudes in relation to its various components and related topics is useful as an analytical tool; and as a predictor for the life situation of disabled people in a particular community. The only problem is when it comes to more complex matters, where (Ingstad, 1995) states that we must define the concept much more clearly than is usually done in writing about attitudes toward disabled people. She suggests attitude be defined as ‘*a statement about disposition to act toward a person, group, or object*’. The term statement reminds us about the nature of our data. Perhaps in this way, we may avoid the danger of

confusing statements with action, and the tendency to conclude that the life situation of disabled people in the community is the result of a single cause and effect.

### **2.3 - The African Perspective**

Devlieger, P. (1995) states that '*a society reveals itself in the way it handles certain phenomena, and disability is one such phenomena*'. Looking at disability from a cultural point of view starts with asking questions like; **(a)** what does disability mean in a certain society; **(b)** how is the status of the person with a disability determined by the culture in which he or she lives; **(c)** what are the most important issues when talking about disability in a certain society.

The Western concept of disability is to improve on the lives of people with disabilities. In some African societies, e.g. the Songye of Zaire (Devlieger, 1995) the primary interest is in explaining why they are as they are. Traditional medical treatment of illnesses is very common in this society, and disability might at the onset be treated as if it were an illness. However the idea of rehabilitation as a continuous effort to improving and accommodating the living conditions of people with disabilities is basically a Western idea that is foreign to them. Instead the Songye have developed in their culture alternative ways and means of coping with disability. Living with the limits of the disability rather than surpassing them seems to be the most important norm. The Songye have an interesting conceptualization of children with disabilities. For them, deviations in the body can induce a higher, lower, or undetermined status in comparison with able bodied people. As a result of this, not all deviation is stigmatizing, and not all persons with disabilities are marginalized because of their disability.

For the Songye, the most important issue concerning a fault is answering the question 'Why?' A search for an answer is important to them. This question is afforded fewer answers in a Western context (Ingstad, 1988) and receives, therefore less attention. In the African context, their search for reasons often lends itself to explanation in terms of the supernatural (Cheater, A.P.1986). Since the question 'Why' central, not much attention is given to the person with the disability as an individual. That person is integrated into normal life in an indifferent way, without ceremonial, without a lot of medical attention, but without being hidden. The reason

for the disability will be sought through analysis of various hypothetical levels of relationship between human beings and their environment. Relationships with the physical environment, family members and ancestors will be examined.

If none of these relations is identified, as distorted, then God is seen as the cause of the disability. Looking at their beliefs in depth, it is clear that these beliefs function as a strong social control mechanism, as well as a restoration of relationships in the community. The relational nature of explanations of disability has been emphasized as characteristic of African cosmologies in general and has important implications for other things like rehabilitation programs.

One of the strengths of an African understanding of disability is the recognition that it is not simply an abnormality of the individual body but also a disruption in the family. More attention should be paid to the relational context in which the person with a disability exists, and greater efforts should be made to involve and support important others. An African approach to disability is concerned with the meaning that biological deviations have for society, for the family, and for the individual. This is a contrast to the modern Western approach which is technical, focusing on the improvement of functions and activities of daily living.

#### **2.4 - The Zimbabwean Tradition**

Dengu, K.G. (1977) in his study of children with disabilities in the then Rhodesia; found three major ways of traditional treatment of children with disabilities to be; (a) killing the child at birth; (b) treatment by a traditional healer and hiding the child within the family circle; and (c) keeping the child in the family but allowing the child to do simple home chores. He states that with the introduction of Christianity and Western ideas this pattern has changed. Children with disabilities are no longer killed but considered to be a gift from God. However, the feeling of shame for a child with disabilities often persists and the disabled child remains hidden away. As for the causes of disabilities among these children, these were witchcraft; misconduct of the parents; the influence of bad spirits and immaturity or old age of the parents. Misconduct of the parents refers to the following three types of behaviours; breaking cultural taboos like killing a snake or staring at a disabled person; incest or extra marital

sexual relationships and not having had enough sexual intercourse during the first months of pregnancy. The important role of the traditional healer is emphasized seeing that he provides answers to the *'how to cure'* and most importantly the question of *'Why did it happen to us?'*

Burck, D. J. (1989) in her studies of general nature and causes of disability in Zimbabwe, found that two main causes of disability were mentioned. These were natural and cultural causes. Natural disabilities are disabilities that according to the informants have a purely physical cause and that require only simple medical treatment by a scientific medical practitioner or a traditional healer as well as those disabilities that are considered to be beyond treatment. Although during the identification exercise the majority of the disabled persons and their relatives indicated that their disability had a natural cause, subsequent interviews revealed that the majority of disabled person in actual fact believed that their disability had a cultural cause. This is very interesting to note.

Cultural disabilities meant that apart from a physical defect, the condition reflects/reflected cultural or social problems in the family and/community and the interference of humans or spirits in the causation of the disability. The natural and cultural conditions and causes should not be seen as mutually exclusive. The respondents initially thought that their illness or disability had a natural cause. Only when the condition continued or got worse, cultural causes were considered. They still believed their condition was polio, rheumatism or epilepsy, but they wanted to find out why this particular person at this particular time had to get this disease or disability. Sometimes when misfortune is expected by a family in relation to certain happenings in the past, the traditional healer is only required to confirm what the family was already thinking. In such cases the medical diagnosis and the medical treatment are completely subordinated to the cultural explanation and treatment, but generally the two can go side by side.

The discussion of the treatment of people with disabilities among the Shona would not be complete without an investigation of the religious beliefs and their role in both traditional (rural) and the modern (urban) life. Gelfand; (1973) and Bourdillon, MFC. (1993) state that the most common religious beliefs are centred on family ancestors (vadzimu). Fortunes and misfortunes in the family are connected to happy or unhappy ancestors, respectively. Illness and / or death or any other mishaps that are considered misfortunes can be attributed to unappeased grandparents or great grandparents of the wife or the husband. Making amends or



healing is in the hands of a svikiro/mhondoro (spirit medium), or an n'anga (traditional healer). When misfortune or illness is persistent in a family, the head of the family leads some of the members of the family to consult a traditional healer in ascertaining the cause of the problem.

Disability in children is also regarded as a misfortune. Jackson, H. (1990) states that there are many explanations given for the presence of a child born with or acquiring a disability. Some of these include witchcraft. (A bad spell from enemies or unappeased ancestors) or a punishment from God to the family or parent. The mother of the child is usually blamed for the disability and often takes on the responsibilities.

There are differences in attitude towards a disability depending on whether or not it is perceived as a troubling disability in that it causes problems for others and takes the mother away from carrying out other chores necessary for the survival and daily life of the family. In accordance with this notion we observe that treatment of persons with severe disability in the traditional agricultural rural setting is determined by their ability to contribute to their family needs. For example, a child with a severe physical disability would demand much more time of the mother than would an otherwise physically fit deaf child.

Children with cerebral palsy and neurological disabilities are considered more disabled than a deaf child. This is because the latter can carry out chores such as herding cattle, ploughing in the fields or carrying out errands. The former is seen as solely dependent on other people for basic needs. However it is also important to mention that in addition to the above perceptions of various types of disability, each family would have their own constructed notions of disability that might influence the treatment of and relationship with the disabled child. This observation has also been made in other cultures such as Batswana (Ingstad; 1995).

This background information shows us the importance of cultural beliefs and traditions in rural Zimbabwe. Ingstad's notion of culture as a neglected and misused variable comes to the forefront. In order to carry out a study of coping behaviours, it is essential to include cultural aspects in order to get a full understanding of what really takes place at the grassroots level. On the other hand, one must not assume that all behaviour is determined by cultural values alone.

## 2.5 - Models of Disablement

Miles (2000) believes that all cultures construct and '*juggle*' with models and metaphors in an attempt to interpret human life and activity. A well constructed model should provide useful insight into a number of users in a particular culture, society or field of knowledge. He goes on to suggest that it is these '*users*' or principal '*care givers*', whose perspective and experience must become the focus of a model of disability. Johnston (1996) considers that a model may serve to explain observed phenomena and so it is vital that the model must be underpinned by the experience of the parent who cares for the child. This need for the lived experience to become the focus for a model is central to its value, credibility and usefulness. Research needs to go further and ascertain these actions before coming to a general conclusion. Therefore models should be used as an aid to understanding a phenomenon. In other words, they are tools to think with.

Models of disabilities have been present since the beginning of the twentieth century. Their adequacy in representing people with disabilities still falls short, especially when it comes to children with disabilities and their parents. An alternative model of disability will not make life suddenly easier for children and their parents, but may serve in the goal of understanding disability from the parent's perspective. Bancroft and Carr (1997) contend that the application of a model as a form of representation for example as a political tool is particularly useful when considering the child with profound impairment. Children rarely seek treatment themselves, thus children's '*problems*' are almost always defined by other people involved with the child. Therefore the use of a model in this case may help to widen perspectives of situations and encourage understanding.

Disability scholars have long argued that what is called physical or mental '*disability*' is not simply an attribute of a person but a complex collection of conditions, activities and relationships, many of which are created by the social environment. This is sometimes called the '*social*' or '*social – political perspective*' in which disability is seen as a '*social construct*', or more pointedly, as a '*sophisticated form of social oppression*' (Oliver, 1986; 1990a). Early treatments of the model, such as found in (Becker 1963) and others relied on medical sociological accounts of the '*sick role*' that originated with (Parsons 1951). This was

complemented by the work of (Goffman, E. (1961, 1963) who described the process of stigmatization as a reaction to deviance.

### **2.5.1 - The Individual Model of Disability**

arose from the medical or individual model and was reinforced by WHO in 1980. The model portrays disability as a personal tragedy-the individual person is dependent upon others for support (Oliver, 1996; Shakespeare et al.1999) and is viewed as a victim of great misfortune. The model is not suitable because it assumes that all the difficulties a child has, are due to impairment.

### **2.5.2 - The Social Model of Disability**

was pioneered by the Union of the Physically Impaired against Segregation (UPIAS) (Finkelstein, 1980; Oliver, 1990), focuses upon the environmental and social barriers that exclude disabled people from society. The model succeeded to shift the debate about disability from biomedically dominated agendas to discussion about politics and citizenship. The model views disability as external to the individual, located in the physical and social barriers that marginalise and oppress.

### **2.5.3 ICIDH**

This resulted in the birth of the **ICIDH** (1980) by the WHO which incorporated a version of the model. In 1993 ICIDH was revised to **ICIDH 2** and this was released in 2000 and it focussed on the areas of mental health, children and the environment. This proved to be unpopular due to its 'labelling' nature. In 2001, WHO further revised the two social models to ICF which democratises disability and that many kinds of conditions qualify.

### **2.5.4 ICF**

The **ICF** stands a chance of being more or less culturally inappropriate when faced with real life challenges. Ingstad, (2005) states 'that we must be careful about forcing issues that are important for us upon people with a disability in other countries'. This means that models do need to be adapted to the particular circumstances of a community. As a result of this, a model for coping with disability (Ingstad and Sommerschild; (1983) was chosen for this study.

### **2.5.5 - The Model for Coping with Disability.**

The model brings in both a synchronic (systems) and a diachronic (time) perspectives. It includes the disabled child as part of the household unit which is also a part of the neighbourhood, and makes the household the main focus of investigation. The model, (see appendix) allows the integration of socio-economic, political, ecological, cultural, emotional, and personality factors in the analysis. The factors can equally be seen as constraints and possibilities in generating social forms that may be identified as patterns of coping with care for the disabled child. The model also adds the possibility of perceiving emotional patterns as well as personal character or style as influential in generating the observed forms of behaviour.

### **2.6 - Social Suffering and Structural Violence**

The concepts of social suffering and structural violence have also been used to analyse the results of the study seeing that the participant's suffering is not of their own creation but was created by the government and its '*disabling*' policies. Some of the sources of human suffering caused by poverty are noted to be discrimination. The Tonga are discriminated against in many areas of resources like lack of clean drinking water, health and education. They also suffer inequities like being given a little food compared to other districts in the rest of the country. Most of the time they do not receive any. It also showed the importance of looking at a people's history in order to see where their problems are coming from so that they are not blamed for their predicament.

Social suffering is the result of what political, economic, and institutional power does to people, and reciprocally, from how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that are usually divided among separate fields; health, welfare, legal, moral and religious issues. They destabilise established categories (poverty, war, torture etc.). Health is both a social indicator and a social process. Social suffering is at the same time about collective and individual (Kleinman, Daas, and Lock 2006).

Structural violence is the negative impact – beyond their own control – of social structures (political, religious, and cultural) on the lives of individuals and groups. Structural violence is what generates social suffering.

The two perspectives were used to analyse part of the results of this paper. This was important in the sense that in order to sort out a problem, one needs to find out first where the problem emanates from, i.e. a people's history. It was also important to ascertain social suffering among the participants and find out how they were coping with care of disabled children in an atmosphere of such abject poverty. This is important in a sense because in some cases mothers of disabled children have been known to be blamed for mistreating their children; when it may not be the case.

There are different perspectives on suffering, and some of them are as follows; when the world suffers, politics is to blame. When a nation suffers, politics and natural disasters are blamed. When a community suffers, politics, natural disasters and tradition is blamed. When a household suffers, it is attitudes and poverty. Lastly when an individual suffers, this is blamed on their personality.

**The case of Anita;** 'Social suffering' and 'structural violence' bring in a new perspective in that it takes politics \ power down to the household and individual level. Farmer, (1992) gives a good example of social suffering in the case of Anita. Anita is a poor village girl who recalled her time at home as a little girl as being frightened by her parents' arguments during the dry seasons; a time when food would be scarce. She remembers times when her mother wanted to buy the children shoes whilst her father wanted to buy seeds instead. After her mother died, she states that they got poorer. As a result of this, Anita left the village for the nearest city to look for work. Whilst working as a maid and trying to help her family back home, she contracts AIDS. Not able to afford the hospital fees, Anita is seen to return home and dies a decent death.

In the case of Haiti (Anita) and many African and Asian societies, where individual rights are often underemphasised and also frequently unprotected, and where the idea of personal accountability is less powerful than is the idea of the primacy of social relationships, blaming the victim is not right. Farmer, (1994) paints a picture of a country with low levels of literacy, low wage-paying employment and high out-migration. Food production is affected by cyclones and droughts. Over 50% of the deaths are among children under the age of five, with nearly 75% of deaths associated with or caused by malnutrition. Infectious diseases account

for the majority of deaths; and the major causes of infant mortality is diarrhoea, pneumonia, tetanus; and tuberculosis is the leading cause of death among adults.

Anita and her family as well as the rest of the villagers were suffering the above hardships due to their forced evacuation from the valley where the community lived and farmed for generations. This was done by the government so as to build a dam that would provide the country with electricity. The irony was that the villagers never benefited from the electricity for this went to the cities. A number of people were not compensated for their lost land; and those that did, did not get much. This situation led to poverty and deaths from diseases as well as HIV/AIDS as the young people were trying to survive in the cities.

The researcher used social suffering in this case because it resembles the situation of the Tonga (see introduction) in that they were stripped of their rights as a community and have been blamed for their misfortunes. The families' problems are blamed on their attitudes and poverty, and at individual level it is their personality. They are made to feel like '*victims*' and yet it is the government and its '*machinery*' that is responsible for their suffering. As noted before; poverty, lack of food, resources, health care, and education etc. problems are found among the community.

### **3.0 - METHODOLOGY**

#### **3.1 - Research Methodology and Theoretical Approach**

Kalnins, (1986) states that in qualitative research; *‘The researcher must get close to the people whom she studies; she understands that their actions are best comprehended when observed on the spot – in the natural, ongoing environment where they live and work. The researcher herself must be at the location, not only to watch but also to listen to the symbolic sounds that characterise this world. A dialogue with persons in their natural situations will reveal the nuances of meaning from which their perspectives and definitions are continually forged’.*

The major purpose of this study was to investigate cultural beliefs and coping behaviour of families with pre-school disabled children. In other words it focuses on the household and sees coping with care for a disabled child as an interlinked aspect of coping with life in general. As a result, the researcher used Ingstad and Sommerschild’s (1984) *‘model for coping with disability’* which takes a holistic view of families’ coping with disabled children.

Ingstad (1997) states that *‘the efforts of family members, to a large extent, depend on the life situation and available resources (material and manpower) of the whole family unit, as well as on decisions made by policy makers and other people with power to decide in matters that concern them’.* In order to bring out the families’ life situation, available resources and political situation in order to ascertain family coping; the study had to be exploratory and use a qualitative approach to achieve its objectives. The researcher chose the qualitative approach because, as Gerson and Horowitz (2003) state; *‘it always involves some kind of direct encounter with ‘the world’ ---it is also concerned with the ways that people construct, interpret and give meaning to experiences’;* which is what the researcher was after, i.e. family experiences of living with children with disabilities.

In order to gather the required information, I decided that I needed to get closer to the people I was studying. I needed to observe them in their homes as well as social places like the church, beer drinking places as well as when they carried out their everyday chores like going to fetch water, climbing trees to get food and weaving baskets. I was not just going to watch them but

get involved in order to get data that contained quotes, stories, visual representations and material culture.

As a result, the researcher chose the most prominent qualitative methodologies of which are participant observation and in-depth interviewing. These were chosen because according to Gershon and Horowitz; *'they share a core of epistemological assumptions that make them complementary and interconnected ---they are intertwined and mutually supportive---in the end, a good qualitative study requires some of both approaches'*. Focus group discussions complemented the two. Tape recording, photography and video camera complemented the data gathered. This was going to achieve an in-depth perspective as well as the process of coping with a disabled child.

### **3.2 - The Researcher**

As a researcher, I shall begin by documenting my own position in doing the research on which this study is based, i.e. my professional background and personal motivation.

Trained as an occupational therapist in England, I spent five years working in the community (Social Services) together with physiotherapists, speech therapists, social workers, nurses, doctors, social services management staff; as well as architects, engineers, builders and painters for housing for people with disabilities. After this I worked (up to date) as a lecturer to undergraduate Occupational Therapy students. In this position I have worked with mothers of cerebral palsy children as well as other disabilities. The desire to carry out this study was the result of my carrying out a research on 'Living Conditions among People with Activity Limitations in Zimbabwe' (Eide, et al.2000 – 2003). The study was based both in the urban as well as rural areas. What struck me most was the struggle of mothers in the villages to looking after their children with disabilities. I felt that I needed to know more about how families were coping with the challenges of having disabled children.

The researcher, like the participants, (although it is envisaged that some participants could be males) is Zimbabwean, Shona and female. The researcher is not of Tonga culture, which poses a language challenge (can understand but not fluent). This made one a stranger, who needed to learn more about the customs so as to understand the people. The disadvantage of this was that the researcher could miss out on some information seeing that one was not able



to catch the information independently. There was also the danger that the researcher could become '*comfortable*' with the participants which could result in missing out on important issues that may have needed clarification.

This problem was solved by having a research assistant who is Tonga, (50+ yrs of age), born and bred in Binga and has spent all her working life years in the district as a community health worker and later at the district hospital as a rehabilitation technician. She works at the hospital as well as carries out outreach work with '*disabled families*' in the nearby villages. However, by the end of the study, the researcher could hold a little conversation with the participants and this made everyone involved very happy.

As a Black Zimbabwean woman carrying out research in my own country, the assumption was that I would find my fellow Black women willing to participate in the study; unlike Reynolds, T. (2002) who had to overcome initial resistance from older mothers aged 50 years and above. In her study to investigate the mothering experiences of Black women living in London, she had assumed that it would be easy for her as a Black woman to find other Black women willing to participate in the study. She found this assumption challenged. The younger Black women welcomed her request to be interviewed, unlike the older mothers who reviewed her request with a sense of unease, suspicion and mistrust. Reynolds had to overcome this problem by turning to people who were well liked, trusted and respected within the Black community. She had to turn to '*gatekeepers*'.

Walsh, D. (1998) notes, unofficial '*gatekeepers*' also exist in various group settings to ensure that their particular group or community is being represented in the best light. In the case of this study, the researcher had to approach '*gatekeepers*' who included the district administrator, the chiefs, and the headmen. The researcher did not find any resistance from any of them; hence the study went ahead without a hitch. After explaining our presence to the homesteads, the villagers, especially the old ladies were seen to readily accept us into their homes. It was nice to see the old ladies upper front toothless smiles. The main advantage was the presence of the research assistant who is well known in the district for her work at the hospital as well as the villages.

Being an outsider was an advantage in this case because it is an assumption that since cultural assumptions, beliefs, and behaviours are embedded within a cultural group, they are not

always evident to those who are a part of the group. This enabled the researcher to compare and contrast two or more cultures. According to (Krueger, 1994) the research will be easier, and the differences more evident if the researcher is an outsider. The researcher found this to be true. It was interesting to note the differences and ask more questions so as to get a good understanding of the phenomenon. A good example was the dynamics of a matrilineal society and child care. The researcher is from a patrilineal society whereby children belong to their fathers.

The researcher and her assistant lived in the villages with the participants. The driver stayed and slept at the nearest clinic. At the beginning, the researcher and assistant visited the participants to carry out in-depth interviews at their homesteads. The three of us would then drive back to the nearest clinic and spend the night there. This was to my advantage because I had the advantage of asking questions and get issues explained to me by both of them. This enabled the team to build up rapport with the participants for future meetings like participant observation and focus group discussions. If there was a funeral, beer drinking party or school open day, we would join in so as to chat to different people. Village social gatherings were very informative and one had a good laugh at a beer drinking gathering; and on the other hand one wanted to cry especially at a funeral. This also gave me the opportunity to build up friendships as well as enabled me to ask informal questions and observe daily life activities.

According to Tonga culture, a true adult is a person who is married and holds a ranking position within a household based on this marriage. I attended most of the ceremonies held wherever we were if we had the time. On the other hand the Tonga were not holding most ceremonies due to lack of sorghum a grain that is used to make beer for the different occasions. The drought as well as lack of food made it difficult to carry out these rituals. On the issue of being single, the Tonga women just told me to go home and get married.

Being Zimbabwean did not give me automatic entry into the studied community. Like any other researcher, I had to work hard at being accepted by the community, and to remember that the participants, not the researcher are the experts on their own lives. I entered a world that I was not naturally a part of therefore I needed to present an identity that permitted relationships to develop. One of the things I did was to adhere to a dress code of wearing long dresses or skirts. The other thing was that I could eat their type of food like green or dried wild okra leaves with maize meal porridge (thanks to my maternal grandmother). Coming

from a patrilineal society, I had to be careful not to lay down one's own values. The Tonga women stated that it was refreshing for them to have me staying with them because they are used to White women visiting them and asking questions (but not lately). This is due to the political situation in the country.

### **3.3 - The Research assistant**

Rehabilitation technicians are professionals educated up to 'O' level, after which they have a further two years training at the local college. Altogether they have 13 years of education. Initially the researcher recruited two female research assistants so that in case of illness one could take over. The study was carried out by just one assistant until it was finished. She was in her 50's had more than 20 years work experience and very knowledgeable. Having a female assistant made it much easier when communicating with the mothers as well as the rest of the family. The assistant's job was to carry out introductions at each homestead as well as assist in using the tape recorder. She also acted as an interpreter where the researcher could not understand the words used. By the time the study finished, we had become good friends.

Initially, the researcher recruited two female rehabilitation technicians who were born, raised and worked in the district but ended up working with one. This was because the assistant had time off from the department and was working in the community recruiting children with disabilities who had not been registered at the rehabilitation department. She did this when I was not carrying out my study. This in a way enabled me to see up to maybe 50 children with cerebral palsy as well as other types of disabilities. We could have seen more but due to fuel shortages, we could not follow all the children that were referred to us by the community.

Working with a native helps in negotiations for entry and access to the participants, for they are familiar with appropriate behaviour within the community. This made it possible for the researcher to observe, interview and participate in activities. The researcher as well as the assistant made two preparatory visits to the community, establishing contacts with the district administrator who had to be given a copy of the research methodology paper and answer a few questions pertaining to the study. The other visits were to the chiefs and the headmen in the villages in order to introduce the study to them as well as ask for permission to enter the villages and carry out the study. Permission was granted by all including the Matebeleland

North medical director. Mapping as well as locating the participants was carried out before the study commenced.

### **3.4 - Research setting**

The study took place in the district of Binga in Matebeleland North Province in Zimbabwe (see introduction chapter). Families were seen in the different villages for example, Kariyangwe, Tinde, Manjolo, Nsenga, Dongamuse and others.

Participants were recruited from different villages in the district as stated above, making the study multi-sited. This meant long distance travelling from the base (Binga hospital) to all the different villages. As a result, a vehicle in good condition and fuel used up most of the study funds. On several occasions the researcher had to buy the fuel double the price on the black market when the one garage outside the district did not have fuel. This resulted in the team having to carry out interviews and staying and sleeping at the nearest clinic to where we would be instead of driving back to Binga. At times we would be away from home (Binga) for two weeks at a time.

The Matebeleland North Provincial medical director had given the directive that we were to be helped with accommodation when needed during the study. This was because the study as well as the assistant was carrying out her work of registering children with disabilities in the district. This was the brilliant idea of the Province's chief therapist. As a result the study was benefiting the Ministry of Health; vice versa. The driver was one of the hospital ambulance drivers on leave from his job. As a result he knew the whole district and he too was a mine of information as regards the health situation in the district. The study was conducted during the period of August to December 2005.

During in-depth interviews the research team, i.e. the driver, researcher and assistant stayed at clinics in the district. The team would sleep at the clinics and visited participants during the day. The interviews were carried out at the homesteads. During participant observation, the driver would drive and leave the researcher and assistant at a homestead during the day and go back to the clinic. The two would then stay with the participants, sleep at the homestead until the following late afternoon. We could not stay any longer at each homestead due to participants' lack of food and the researcher was unable to carry much either.

We carried two kilograms of maize meal and a kilogram of sugar for each family. This was to help with breakfast, which the participants could not afford at all. The children loved the porridge with sugar. The weather was very hot (up to 42C) and so we all slept outside in the courtyard. We spent one night inside when we visited a family in the mountains. This was due to the fact that elephants visit the homesteads at night looking for food and can attack people. Wild animals like lions do visit as well to catch goats.

Three focus group discussions were held at two clinics and the main district hospital. The researcher provided food and drinks for the participants. A cook was employed for the day to do the cooking. The researcher visited the Tonga museum located in Binga growth point to get information on culture. This was near the hospital where the researcher was based when not at work in the villages.

The researcher also visited Chipanda Ward where she met pregnant mothers from around the district who had come to give birth at the hospital. This is an outside ward where women from far away in the district come to stay whilst waiting to give birth at the hospital. They do their own cooking outside and sleep in the dormitory ward. This was done several times so as to chat with the mothers to find out their general life situations at home. Mothers in law were the main escorts to the young girls. Older mothers arrived on their own, had the baby and walked home or got on public transport like lorries. Buses were no longer reliable due to fuel shortages.

The hospital wards especially the maternity and children's wards were visited for more information on birth complications and mortality statistics. Other departments visited were the environmental health department for information on malaria and other diseases; the nutrition department providing the 'Binga' nutritious porridge; the researcher went out for a day with the family planning assistant from the family planning department (very unpopular with mothers in law who insist on many children); expanded programme on immunisation (EPI); and the rehabilitation department at the district hospital.

The major purpose of this study was to investigate cultural beliefs and coping behaviour of families with pre-school disabled children in a rural setting in Zimbabwe. The study gathered information on traditional beliefs about the causes of impairment, as well as attitudes and behaviour towards children with disabilities and identified factors that are of importance in determining the coping ability of these families in general and the problems of disability in particular.

### **3.4.1 - Objectives**

The specific objectives of the study were to explore the following;

- ✚ The beliefs and attitudes held by or exhibited by the families of disabled children as they relate to disability.
- ✚ The effects of caring for a disabled child on the family's activities of daily living.
- ✚ Factors that may influence the caring of the disabled child; e.g. social, economical political etc.

### **3.4.2 - Research Questions:**

The semi-structured interview was in the form of three themes;

- ✚ Parents view of disability and its causes.
- ✚ Life before the child with disabilities was born.
- ✚ The experiences of living with a child with disabilities.

### **3.4.3 - Study population**

The study population included families of pre-school children with disabilities, both boys and girls. This included the gatekeepers such as mothers, fathers, grandmothers, grandfathers, aunties, and uncles as well as the rest of the family who were looking after these children. 30 families were included in the study.

### **3.4.4 - Criteria for Inclusion and Exclusion**

Families were included in the study if they met the following criteria;

- ✚ They live in Binga district.
- ✚ They had to be Tonga.

- ✚ They had a child with disabilities i.e. cerebral palsy.
- ✚ The child with disability was of pre- school age.

Families were excluded from the study if they met the following criteria;

- ✚ They lived outside the district.
- ✚ They were not Tonga (may have moved into the area from other districts).
- ✚ Did not have a child with disabilities.
- ✚ The child with disabilities was of school going age.

### **3.4.5 - Sample size**

Sampling in qualitative research is usually purposive. In this case sampling was purposive in order to get a broad range of information and perspectives from the participants. In purposeful sampling, the investigator selects participants because of their characteristics; good informants \ participants are those who know the information required, are willing to reflect on the phenomena of interest, have the time, and are willing to participate; (Spradley, 1979).

Cerebral palsy was the disability that was included in the study. As stated before, Binga is an area where hunger is rampant, and as a result there was a possibility of including children with malnutrition in the study. In order to get children with the right diagnosis, the researcher and assistant chose thirty families who had had a diagnosis of cerebral palsy made by the doctor. 10 had been born at the district hospital and so had their diagnosis made by the doctor. The other 20 had either been born at home and later admitted to the hospital or had been diagnosed later (4 -6 months) when parents noticed the child's problems. The researcher tried to make it as representative as possible by picking families from all the areas of the district; i.e. north, south, east, west and central.

## **3.5 - Data collection techniques**

### **3.5.1 - In - depth Interviews**

In-depth interviewing is a data collection method relied on quite extensively by qualitative researchers. Described as 'a conversation with a purpose' (Khan and Cannell, 1957, pg 149) state; *'in-depth interviewing may be the overall strategy or one of several methods employed*

*in a study. The researcher explores a few general topics to help uncover the participant's meaning perspective, but otherwise respects how the participant frames and structures the responses'. In this study the researcher posed three themes to the participants whereby information was elicited, an example was the meaning of disability.*

The first theme was the parents' view of disability and its meaning. The second theme was life before disability and the cause of disability. The third was the experience of living with a child with disabilities. The researcher chose in-depth interviewing as one of the data collection techniques because it is a useful way of getting large amounts of data quickly. In this case more than one person in the family could participate, for example the mother, father, grandmother and the extended family involved in the care of the child. At some homesteads one would get information from three generations.

The other advantage was that immediate follow up and clarification was possible if more information was needed. Combined with participant observation, interviews allowed me to understand the meanings the Tonga hold for their everyday activities. For example on the parents' view of disability and its meaning, it was interesting to get the information from both the parents (young and old) as well as the grandparents.

The difference between interviewing and participant observation is that; in in-depth interviewing, the researcher can formulate her research problems in a variety of ways e.g. she can begin with a set of theoretical and historical questions about the nature, causes and consequences of some important but poorly understood phenomenon. In this case it was *'disability and its causes; life before child with disability was born; parents reaction to disability news; life after child with disability was born or when disability was diagnosed'*. The researcher put the questions in such order because chronologically ordered questions provide a structure for recounting a coherent narrative and for remembering potentially important, but easily overlooked events and experiences. The researcher found this very effective especially with old people.

On the other hand, in participant observation, the researcher begins by choosing a site that helps to explore gaps in theory. Upon entering the field, one asks the question; *'what is really going on in a certain community---how do people make sense of their social worlds---what limits and what helps to create the social worlds of the people'*. The question that this



researcher asked herself as she entered the field for participant observation was *'How can people live in such poverty---how do they manage?'*

Interviewing depends on developing a research design from more general empirical and theoretical concerns and thus relies on a more deductive approach. An observation study can begin as soon as a research site is chosen and then proceed more inductively as what is really going on becomes clearer and a set of more specific questions and insights begin to emerge.

Bryman (2004) states that interviews tend to be much less structured; 'rambling' or going off at tangents is often encouraged; interviewers can often depart significantly from any schedule or guide that is being used; the qualitative research interview tends to be flexible, responding to the direction in which interviewees take the interview and perhaps adjusting the emphases in the researcher as a result of significant issues that emerge in the course of interviews. In interviewing, the researcher wants rich, detailed answers and the interviewee may be interviewed on more than one and sometimes even several occasions.

One of the disadvantages of in depth interviews in the study was the small sample size (30). The researcher found that certain distinctive features in the data can make it difficult to avoid identifying individuals in a report, compromising anonymity. This has ethical implications for the study participants. In this case the use of fictitious names was an option. Marshall and Rossman (1995) state that interviews involve personal interaction and that cooperation is essential. This can be a problem in the sense that it has implications with regard to violating participants' right to privacy. This problem was solved by the researcher having a Tonga assistant who acted as an advisor. For example I remember being advised not to ask for permission to look into participants' granaries for the simple reason that some participants kept witchcraft medicines inside granaries.

There is also the point that participants have to reflect on whether or not to share personal information and to what extent. This was overcome by the use of participant observation and focus group discussions whereby information was corrected or clarified. As a researcher I thought that I probably would have problems getting the Tonga to give responses that would reflect their own feelings, attitudes or practices seeing that this was a political issue. I was glad to see and hear that what they were saying tallied with their situation. They managed to express the notion of social suffering by an oppressive government.

Trained as health personnel, the researcher has experience in health and disabilities interviewing of participants. Although this was the researcher's first time carrying out an ethnographic study; one managed the use of ethnographic questions in gathering cultural data. Spradley (1979) identified three main types of questions, i.e. descriptive, structural and cultural which the researcher used. Because of its focus on culture through the participant's perspective and first hand encounter, this approach is flexible in formulating hypothesis and avoids oversimplification in description and analysis because of the rich narrative descriptions (use of Tonga only participants). The researcher did all the data writing up every evening. This resulted in volumes of data collected meaning that it has become a time consuming task which has resulted in computerised data analysis.

### **3.5.2 - Participant Observation**

The sky was the most beautiful sight, well lit with all the stars to see. I seemed to be the last person to fall asleep, maybe it was because I was not as tired as the rest of them. I enjoyed the bleating of goats, as well as the shrilling of the cicadas in the evenings just before the rains. At one homestead, the dog coughed all night and it was as thin as a rack. At another homestead, an old grandmother narrated how children with disabilities were taken from their mothers and put in an ant hole and left to die. The grandfather then sang me a song to such an effect before we all went to sleep.

Developed through mainly the disciplines of cultural anthropology and qualitative sociology, participant observation is both an overall approach to enquiry and a data gathering method. May, T. (2002) says that it has the advantage of being able to directly observe the behaviour of those who the researcher is interested in studying. Participant observation demands first hand involvement in the social world chosen for the study. Immersion in the setting allows the researcher to hear, see, and begin to experience reality as the participants do. Ideally, the researcher spends a considerable amount of time in the setting, learning about daily life.

In order to cross validate and ensure the reliability of responses from the interviews used in individual and focus group discussions, the researcher felt that there was need to collect additional data through the observed, lived experiences, hence the importance of carrying out

participant observation. This also helped me to cross check the information that I had gathered from the interviews.

The researcher can say that this is the part that was very interesting. I lived with the participants in their homes during the four months of the study. I shared their food, ate the wild okra leaves with sadza (staple food); porridge with busika (wild sour fruit) and drank the traditional beer. The best part was having to share the Tonga smoking pipe (ndombonda) with the old ladies; this is where some notions were explained. I noticed that the men and the boys ate on their own as well as the women and the girls. Babies and toddlers were always with their mothers so as to be fed.

After eating, the elders would then talk about the day as well as other important issues. Issues were clarified and wisdom passed onto the younger generation. As their visitor, they would ask questions about me and I did the same to all, i.e. the parents, grandparents, boys and girls. At most homesteads, neighbours came and sat with us in the evenings. This enabled me to observe the whole family dynamics. The Tonga did not come across as people who had something to hide or fear as a result of me writing up the study. Most stated that the authorities know their political inclination anyway. Unfortunately, there were not many cultural activities like brewing beer for the ancestors because of the shortage of sorghum.

I got involved with activities of daily living like fetching water at the borehole and river; going to the gardens and irrigation scheme; as well as guarding the homestead at night when cows invade the homestead for thatching grass. I saw how well the parents looked after their children as well as the disabled child. The mothers were struggling to find food for the family, but still, this was divided so that everyone had something to eat. I talked to the siblings to ascertain how they felt about their brother or sister who was disabled. They stated '*We don't mind him. He is our brother \ sister*'.

I attended social gatherings like the Catholic Church, other conventional churches; funerals; beer drinking parties; the fisheries; a wedding; as well as shopping centres. Getting involved in these activities helped confirm the data that I had collected or added new data to the existing one. I also attended a secondary school's end of year prize giving day. It was sad to see a large number of boys compared to the girls. At the end of the ceremony, the school head as well as the village head reminded parents to encourage children to attend school, especially

girls. He announced the number of girls that had got pregnant and left school as well as those ‘*unaccounted for*’. The researcher noted as well as was informed by the school head that most of the teachers were not trained and that the students’ end of year pass rate was not good. I felt sad for the students.

Marshall and Rossman (1995) state that participant observation assumes that behaviour is purposive and expressive of deeper values and beliefs. In cases of not understanding the behaviour, participant observation is good in that one is able to ask for an explanation. In the beginning the researcher entered the setting with broad areas of interest but without predetermined categories or strict observational checklists. The importance of this is that the researcher is able to discover the recurring patterns of behaviour and relationships. After such patterns are identified and described through early analysis of field notes, checklists become more appropriate and context-sensitive.

The researcher also lived with the assistant and her family at the district hospital. She is a well known and generous person who takes in her relatives from the villages when they need treatment at the hospital. This resulted in the researcher living with these young women who had come to give birth at the hospital; old aunties and uncles who needed hospital treatment; and others. Information was gathered from these people as well. A visit to the assistant’s village home was another visit that added to my learning experience.

The researcher and assistant chose the ten families that were included in the participant observation group. The team made sure that the district was well represented by choosing from the northern, southern, eastern, western and central district. The team made sure that the families included single parents, grandmother headed families, as well as child headed families in order to get a good picture of the situation on the ground.

The researcher did some of the interviews independently, taking notes occasionally, photographs as well as video taping. The notes would be written up in the evenings (candle light) at the clinic just before bed time the following day. This was exhausting because I did not want to lose any data by forgetting. I would get clarifications if needed from the assistant or pass through the homestead again if need be.

### 3.5.3 - Focus Group Discussions

In social science, focus group discussions have been used both as a means of data collection or as a supplement to both quantitative and qualitative methods (Morgan 1993). In the study, this was used as a supplement to participant observation and in-depth interviews. Focus group discussions were used because in this case the study deals with a homogeneous people in a social interaction, the purpose being to collect qualitative data and the aim is to collect data that is both inductive and naturalistic. This becomes a way to better understand how families perceive as well as cope with disability.

In carrying out focus group discussions, participants were selected because they all had one thing in common which was '*children with cerebral palsy*'. The three locations were chosen by the participants because they were central places which they were comfortable with and accessible. It was a mixed group with regard to age and friendship. This was to minimise conformity of response as well as the inhibition by friendship and issues of loyalty. The three groups consisted of eight, eight and twelve participants. An interview guide was prepared before hand. This had been pilot tested and found to be good. The researcher led the groups and the assistant helped when needed. These were taped as well as video recorded and translated into English. The group discussion was conducted several times until the researcher could identify trends and patterns till saturation point. Careful and systematic analysis of the discussions provided clues and insights of their experiences.

The researcher had discussed the issue of coping with disabilities with individuals at their homesteads during in-depth interviews. This time I was interested in the ways in which individuals discuss the issue as members of a group. I was interested in such things as how the mothers responded to each other's views and build up a view out of the interaction that takes place within the group. Bryman (2004) states that in one to one interviewing, participants are rarely challenged and they might say things that are inconsistent with earlier replies or not true; and as interviewers we are often reluctant to point out such deficiencies. In focus groups, individuals will often argue and challenge each other's views. This process of arguing means that the researcher may stand a chance of ending up with more realistic accounts of what people think, because they are forced to think about and possibly revise their views. This was very interesting and led the researcher to make conclusions on some issues that had seemed a bit fuzzy during the interviews for example in 'the search for treatment'.

The researcher noted the disadvantages of focus group discussions as; only a limited number of questions could be addressed; questions could not be explored in detail; nor could interesting leads be adequately pursued. I noticed that special skills were needed in order to handle the group and get the discussion going. Some participants were dominating the discussion so at times one had to ask the others to take part as well. Grbich, C. (1999) states that 'it is the 'public' rather than the 'private' views of individuals that tend to be documented. The interviewer has less control over a group. A huge amount of data is produced and the data is difficult to analyse. Recordings are time consuming to transcribe'.

The advantages of focus group discussions according to Grbich (1999) are that the groups are suitable for groups with a strong oral tradition and low levels of formal education. This is the situation in Binga, i.e. low levels of formal education. The researcher was pleased because the participants were able to participate and put forward their views. They are also time efficient, more people can be questioned in the same amount of time as it takes to interview one person although this needs a skilled facilitator to develop a rich source of data.

In this study, only two mothers did not turn up. They did not send their apologies as a result the researcher and assistant did not know what transpired at home. One group ended up with twelve because two mothers decided to attend the meeting citing that they were not able to attend their scheduled one due to their absence from home at the time. The researcher thought that this was very responsible of them although the group was big. Anyway, one could not turn away a mother with a baby on her back that had walked for miles to get to the meeting point. At the end of the group discussions, the mothers were driven back to their homes.

#### **3.5.4 - Triangulated Methods**

Triangulation was first conceptualised as a strategy for validating results obtained with the individual methods. It can mean combining several qualitative methods, but it can also mean combining qualitative and quantitative methods (Flick, 1992a; 2002). It can also be said to be the use of more than one method or source of data in the study of a social phenomena so that findings may be cross-checked.

This study used triangulation of qualitative methods as well as projects. This was done in order to obtain a comprehensive understanding of the phenomena of families coping with disabled children. As stated before, the qualitative methods used were semi-structured interviews, participant observation and focus group discussions. In project triangulation, Ingstad's Botswana project was partly used. This was done in order to increase the validity of the findings for triangulation may function to confirm or make information more complete.

The data was also triangulated both at individual level through the interviews and collectively through focus groups (as discussed above). It was interesting to note how during in-depth interviews the mothers stated that they had tried all the treatments they could manage for the child and had now given up. During focus group discussions, they then stated that if they can locate any traditional healer who can cure the child, they would still try again. This information in a way confirms the mothers' love for their children with disabilities. It looks like if it wasn't for their poor socio-economic status, they would have continued seeking treatments for the children.

Participant observation also helped to validate information collected during in-depth interviews. The researcher remembers the first time that I was told that children did not attend school because of the long distances. I was shocked, but later found out what the families meant when we started driving round the district and staying at their homesteads. At one village the children had a two hour walk to school starting out at 0500hrs and getting there around 0700hrs. In this case, in-depth interviewing on its own would not have been more meaningful without the data from participant observation. In the later, I noticed the struggle of parents to educate their children.

The triangulation of projects was also very useful since the study has not been carried out by many researchers and therefore it was good to compare the three and find out how the parents were coping with disabled children in developed and non-developed countries. One disadvantage of triangulation noted was that the process was time consuming. However the researcher could manage the study because this was on a small scale.

### **3.5.5 - Field Notes: (Diary)**

The researcher kept a diary throughout the study. I managed to collect texts composed by other people such as songs, stories and other information. This has been of great help in gaining deeper understanding of different phenomenon. A good example was the information on the elimination of children born with disabilities. After the narration of what used to take place, folk tales as well as songs to the effect were sung by the old folks.

### **3.5.6 - Secondary Data: (Documents)**

Secondary data is pre-existing data which may or may not have been analysed or published, and has not been gathered for the purpose of the study in question. This included a review of published ethnographic, historical and sociological literature or government or non-governmental organisations reports. These were systematically evaluated for their relevance to the study. The researcher used such type of data in the background information as well as for setting the research topic in a wider context, and for revising the data collection process.

This included ethnographic and historical materials like Elizabeth Colson's books on Tonga culture, e.g. 'The Plateau Tonga of Northern Rhodesia (Zambia) Social and Religious Studies (1970). Non-governmental organisations' materials were also useful in providing data from the work that has been carried out in the district in the past few years and to date. This was mainly Save the Children U.K. which is based in the district and is now mainly involved with education for AIDS orphans, children with disabilities and other vulnerable children. There was also Ntengwe (NGO) that is involved in community development targeting youths, orphans, vulnerable children and women infected and affected by HIV and AIDS. A few documents were found in the local museum.

The researcher also used official documents deriving from the state like Community Based Rehabilitation (Ministry of Health); malaria (hospital department of environmental health); disability statistics (department of Rehabilitation – Binga hospital); children's health and immunisation (hospital department of community health) and other information from the paediatrics ward on malnutrition. The researcher used the information because it is a source of a great deal of information of potential significance for social researchers. On the other hand



one has to be cautious because interests play an important role in such materials. The question of credibility raises the issue of whether the documentary source is biased (the issue needs its own study).

The researcher also used information from official documents derived from private sources like the World Wide Web (www). The use of the internet added some information. I noted that although this was a good source of material, there was however the need to keep in mind J. Scott (1990: 6) distinctions relating to the criteria for assessing the quality of documents such as authenticity, credibility, representativeness and meaning. There was also use of mass media outputs like newspapers, mainly the Zimbabwean ones. Use of mass media outputs have their downside of internal contradictions in reporting such that one had to be cautious when quoting them. A lot of reading round and discussions with fellow Zimbabweans was done before deciding on what to quote. The researcher also used 'text' as applied to a range of phenomena, Bryman, (2004) e.g. information from landscapes like the Chizarire mountains and its meaning to the Tonga as well as the famous Zambezi river and its crocodiles.

The advantages of secondary data was that it was available locally, inexpensive and grounded in the research setting and provided opportunity for study of trends over time and others. One of the disadvantages was that one had to verify with others making it a time consuming process.

### **3.6 - Discourse Analysis**

Discourses are dynamic dialogues in which meaning is socially and historically produced and reproduced and transformed into interaction (Girbich, C.1999). The researcher used discourses for this study because they are socially conditioned and socially constitutive reflecting the cultural and religious understandings and expressions of a society. Verbal dialogues as well as statements from the participants were noted in the general cultural and religious contexts. This added more clarity and validity to the other data collection methods used.

The Tonga (old men from the valley) always had their story to tell. This was the narration of their eviction from the valley and what the White Rhodesians had said to them fifty years ago; '*Go, the water will follow*'. The researcher was always ready to sit down and listen to the

story over and over. It was sad to listen to their voices changing into whispers at points like, ‘-  
--etc’ *eviction day---death of family members and friends---food scarcity etc*’.

Just like the Tswana study, the researcher found similar discourses on ‘emotional experiences of having a disabled child re’ *‘feeling sorry’* related to their cultural notions of self and personhood, life and death, their previous experiences of having children, their maternal environment and struggle for viability as well as their emphasis on collective responsibility’ (Ingstad, 1997).

There was also the folk tales and songs from the grandmothers and grandfathers that depicted Tonga meanings of their life stories like how disabled children were disposed of by leaving them in the forest, burying them in the river sands or putting them in an ant hill.

### **3.7 - Data Management and Analysis**

Data analysis started simultaneously with data collection until after field work. The researcher collected data from in-depth interviews, participant observation and focus group discussions. The information from the above was translated and transcribed into written text for analysis (word for windows). The data was then transferred to a computer software package, in this case the NUD\*IST (N – VIVO 6). The data was then coded into categories under the ‘tree nodes’ with sub-categories under most of the codes. Some of these were *‘causes of disability--life before disability---life after disability---culture---coping---assets---needs---parents education---age---choice of treatment etc*. This was then further divided to *e.g. coping---family support---financial support---church---others etc*. Data from all the data collection methods was critically analysed to form a theoretical framework that explained the current perceptions of the families coping with their disabled children. Quotations were also used to accompany the summarisation of the discussions.

The participants were identified by numbers in order to maintain confidentiality. The main summaries were verified with the participants for authenticity at the end of the study and comments were noted. Unfortunately, the researcher will not be able to meet for final verification of results with the assistant who is in Zimbabwe and I am in Oslo. I briefly verified the findings with her before coming back to Oslo. The researcher did all the writing

down of the notes and stored the raw data in a safe place before getting back to college to start the computer analysis.

### **3.8 - Dissemination of Findings**

The final report of the study will be communicated to the following;

- ✚ Save the Children (Norway) and other NGOs in Zimbabwe
- ✚ Southern African Federation of Disabled People (SAFOD) Zimbabwe
- ✚ The Government (Ministry of Health)
- ✚ Institutions like the University of Zimbabwe
- ✚ Department of International Health (UIO) Norway

The study can also be presented at conferences, seminars and workshops. It can be published in peer review journals for professionals and other interested parties to read. The researcher intends to co-write a chapter in a book to be published (Disability and Poverty).

### **3.9 - Ethical Considerations**

Ellen, R. F. (1984) States that *'ethnographers should recognise the rights of citizens to privacy, confidentiality and anonymity, and not to be studied; to be informed about the methods and aims of the study, its anticipated consequences and potential benefits, risks and disadvantages, and its source of sponsorship and funding; to be fairly remunerated for time and assistance; to be given feedback on the results and, where practicable, to be consulted over publications; and to have their legal or contractual rights in data respected'*.

The researcher did note the participants' rights and as noted before, participants were identified by numbers and permission to carry out the study was given after the study had been fully explained to them and they in turn signed the consent form. Feedback was given as stated before. A small *'thank you'* token for the participants (during interviews) was discussed with the assistant and we agreed on USD 2 for each participant. At that time, the amount could buy a 25kg sack of maize meal. For participant observation, a packet of 2kg maize meal and a packet of 1kg sugar were given to the ten families.

### **3.10 - Informed Consent**

Bryman states that informed consent is '*A key principle in social research ethics. It implies that prospective research participants should be given as much information as might be needed to make an informed decision about whether or not they wish to participate in a study*'. In this case the researcher had to do the above because I was also going to be staying with the participants in their homes. This also involved their voluntary participation with their right to withdraw from the study at any time, thus counteracting potential undue influence and coercion.

In this study, all the participants were adults who managed to give their consent independently. The two child headed families' consent was given by the grandmothers who were the gatekeepers. With the exception of a few young mothers who had a few years of education, the rest had no education at all and so the research assistant had to explain what the research entailed as well as the consent form. They however managed to write an 'x' as their signature.

### **3.11 – Confidentiality**

Confidentiality in research implies that private data identifying the subjects will not be reported. This can create problems for the participants if this is not adhered to in the sense that this can lead to family disruptions, ostracization from the community and peers. The researcher used a tape recorder, camera as well as a video camera. In this case all the tapes and films were kept under lock and key so that no one would have access to them. These will be destroyed at the end of the study. As for the photographs, these will be handed over to the families and if not, they will be destroyed.

### **3.12 - Ethical Clearance**

Prior to commencement of the proposed study, a research protocol was sent to both the Norwegian and Zimbabwean Research Committees for ethical clearance. Another letter asking for permission was sent to the Matebeleland Provincial Medical Director. The researcher then commenced the study after receiving permission letters from both committees as well as the provincial medical director.

### **3.13 – Limitations**

The study topic is broad and complex. In order to address the topic adequately, the researcher felt that more time, resources and a larger population were needed to get a good perspective. Due to the small sample size, it may not be possible to make a generalisation of the results in a statistical sense, but shows general problems. The study could act as a pilot study for future studies.

### **3.14 - Information gathered from the Study**

The researcher's aim was to investigate cultural beliefs and coping behaviour of families with pre-school disabled children. I was after gathering information on traditional beliefs about reasons for impairments; attitudes and behaviour towards the disabled children; identifying factors that are of importance in determining the coping abilities of these families in general as well as with their disabled children.

The qualitative approach and its methodologies were found to be appropriate and adequate in the sense that the researcher managed to collect the type of data required. The participants managed to explain the meaning of their beliefs, their life stories, disability and attitudes as well as how they lived from day to day. I found that people were much more relaxed in the evenings because this was the time they would have eaten if they had food in the home. Most were having one meal a day (evenings).

The researcher also managed to interact with the disabled child during participant observation. None of the children had been tested for HIV/AIDS so one was not able to tell what was taking place. The medical histories of the children were narrated, giving the researcher insight into how the family coped with the child. Most of these children could have been referred to other professionals for treatment but this was not possible. The parents could not afford to buy food let alone get the child to the doctor for treatment.

The Tonga experiences were mainly captured during in-depth interviews and some information from participant observation where explanations were given sometimes together with folk tales. They narrated their life experiences in the Zambezi valley up to date. The poverty was evident for anyone to see. As a result, participant observation in a way was a bit

difficult in that one would come across a situation that was not conceivable, e.g. a family eating (dry) boiled maize infested with termites. This was dried maize that the wife had gone to beg from her relatives. The researcher and assistant shared the meal and thanked the family.

Focus group discussions showed the solidarity of the participants with each other. I found this to be very sad. The participants showed that they were all suffering. They were all going through the same situations. Seldom were there discrepancies in how they were coping with their disabled children.

I found that as time in the field unfolded, personal feelings also evolved. I found myself developing strong emotional ties; positive ones towards the participants and negative ones towards the government. I was so angry especially in the beginning and felt as though I wanted to leave. At the end of the study I felt that I did not want to leave because I had grown fond of the Tonga and made friends.

In conclusion, I would say that my position as a Black female researcher interviewing Black women provided an interesting challenge to the notion of the '*powerful researcher*' who exercises power and authority over the '*powerless research participant*'. As in (Reynolds; 2003) case, this study revealed that '*powerful researcher*' is not a given aspect of social research and that this is very much contingent upon structural differences such as class and gender divisions.

Being well educated and middle class did not make me assume relative power and authority in my interviews with some participants like the older mothers and grandmothers. I felt intimidated by the wide age difference and the fact that they possessed a wealth of experience. My own cultural background meant that I was brought up to respect my elders and not question them on matters that would prove to be embarrassing or intrusive for fear of appearing disrespectful. As a result of this, I had to ask my assistant to ask questions on sexuality on my behalf. She did this once and the rest of the time I had to ask for their permission first and they readily agreed to answer the questions and responded well. Despite all this, I still felt that in this context power had shifted to them.

On the other hand, I noted that the young mothers positioned me as a middle class and a professionally educated Black woman. They saw me as a figure of authority and allowed me

to control the style and pace of the interview. I still had to ask for permission to ask the same questions on sexuality but this was not as daunting as with the other group.

The above two interactions suggests that power in social research is not a fixed and unitary construct, exercised by the researcher over the research participant. Instead, Reynolds states that *'power is multifaceted, relational and interactional and is constantly shifting and renegotiating itself between the researcher and the research participant according to differing contexts and their differing structural locations'*.

## CHAPTER 4 RESULTS

### CASE STUDIES

#### 4.1.1 – Case of Joe

Joe is a five year old boy who lives with his maternal grandparents who are in their sixties. They have looked after him since he was a year old after his mother left the homestead to get married for the 2<sup>nd</sup> time. Joe's mother was divorced by his father when it was found that Joe was disabled. The grandparents stated the reason for divorce as witchcraft from the neighbours who were jealous that Joe's mother was married. The family stay together with Joe's grandfather's deceased brother's wife and her family. It is a big homestead.

Joe was born at home with his grandmother as the birth attendant. It was a prolonged birth with complications. This resulted in delayed milestones and a left hemiparesis with contractures to both left arm and leg. At three years of age, his grandmother's brother paid for Joe to be taken to Bulawayo Orthopaedic Centre where he was given special shoes to enable him to walk. During the study, Joe was not using his shoes because they were now a smaller size and this created mobility problems for he could not walk far. In 2003 the shoes were still free and the grandmother was given a bus pass to use to and from Binga to Bulawayo. The situation has now changed. One has to pay for both the shoes and bus fare. As a result the family cannot afford it, meaning that Joe will never be able to walk properly even for short distances.

The grandmother states that the community sees the child as disabled and praises her for looking after him. She states that life before Joe was born was not difficult. Life had changed with the fact that they now had to find money to take him to the clinic when he is not well. The grandmother has to stay at home more often because she cannot leave him on his own or with other children because there is a danger that he can fall into a fire or bucket of water. Having to put him on her back was the most tiring task. Treatments sought by the family were, traditional healer, the hospital and Orthopaedic Centre. The other problem is that Joe gets severe monthly headaches, has to lie down and pain relief is not easy to get (expensive). He also presents with some degree of learning disability.

Future – the grandparents see their grandchild going to school. The grandmother stated that she will sell her chickens for the fees. The family needs were food and clothes. They did not have garden vegetables because the river had run dry. They occasionally buy vegetables from a nearby irrigation scheme when they can afford to. Joe's grandfather says he is happy for Joe is good company for him.

#### 4.1.2 – Case of Annie

Annie is a 3 yrs 9 months old girl who manages an unsteady slow walk with difficulty, salivates most of the time, manages a weak smile, has no speech and has learning difficulties. She lives with her 22 year old divorced mother at her uncle's (mother's brother) homestead. Her maternal grandparents live nearby. Annie's father left her mother when he found out that she was disabled. Annie's father had two wives and her mother was the 1<sup>st</sup> wife. Annie was born at home with numerous complications and taken to the hospital after two weeks. The



explanation for Annie's disability was witchcraft by the co-wife. The husband's family are not interested in her and say that disability does not run in their family.

Annie's mother states that life before she was born was not so bad. The husband was working at the river docks and paid a little which she supplemented with money from weaving and selling Tonga baskets. Annie was taken to the traditional healer and then the hospital. She is a sickly child who is often hospitalised when the mother can afford to take her to the hospital otherwise at times the mother uses the 'popular' health sector. She uses treatments from the Annie's grandmother to treat diarrhoea and fevers. Annie's mother reports that (*mwana murema anashupa sibili*) meaning that life is now very difficult and it is not easy to look after a child with disabilities. She states that her mother and sister in law help with baby sitting when she has to fetch firewood and water (8kms away). The sister in law helps by sharing food and soap when she gets some from her husband who works in town.

Annie's mother used to weave Tonga baskets for sale but these have no buyers now since there are no tourists visiting Binga. Women from Bulawayo used to come and buy them in exchange for clothes and money but this had been stopped by the government by their implementation of 'Operation – Clean Up' (May, 2005), which resulted in these women not allowed to carry on with their business. The family did not have enough food in the house. They had not harvested much due to the erratic rains and elephants which destroy their fields every year. The government had stopped the provision of porridge due to fuel shortages in the country. There is no crèche in the area and the nearest school is 8 kilometres away.

Annie's mother believes that rehabilitation helps because Annie was helped to sit by using a corner seat from the rehabilitation department. The mother admits to shouting at the child especially when she opens her bowels in her pants. She says it is because she sometimes goes without soap so she cannot wash the pants but has to reuse them again. She has a few pots and pans, 3 blankets and a mosquito net for Annie (from WHO). The mother does not see any future for Annie because of her inability to carry out activities of daily living.

#### **4.1.3 – Case of Peter**

Peter is a 3yr 1 month old boy with five siblings older than him. Both his parents did not attend school and his mother did not know her age. The researcher had to use her national identity card. She was 35 years old. The father is unemployed. Peter's mother and her children live at Peter's maternal grandparent's homestead. This is because Peter's father had not paid the bride price so he has to wait until he pays and then can take his family to his people. The father visits and helps at the in laws homestead.

Peter's mother had a prolonged home birth with complications which resulted in delayed milestones and a right hemiparesis. He also suffers from epilepsy. The family believes that the child was bewitched. Peter's mother's younger sister has a right hemiparesis and has got limited mobility. She has a four year old baby girl (out of wedlock). Peter's mother has to look after her six children as well as her older sister and the toddler. She stated that she was not going to have more children because she could not cope anymore.

The family took Peter to the traditional healer and later on the hospital. He was put on medication for epilepsy and the mother reported improvements in that he was having the occasional mild fit unlike before when he had grand mal fits. During the visit to the homestead, the medication had run out two months before and he was having fits again. The

family said they did not have money to go back to Binga hospital for more medication. They were in the process of trying out traditional medicine but reported that there were no improvements. The research assistant advised them to attend the hospital as soon as possible and contact her for help when they got there.

When asked to comment on life before Peter's disability was discovered she said that life was not difficult because the other five children grew up without any health problems. She could carry on with her house chores as well as 'food for work' at other people's homesteads. Now, she was unable to work for cash as much as she used to do to purchase basics like salt, soap and candles. Peter sometimes has fits in the dark at night because they cannot afford candles. This was now difficult for Peter is hyperactive and can fall into a fire or injure himself. This means that she has to be at home most of the time with him and can only leave him behind with the other siblings when they are at home from school. Her brother works in Bulawayo and he helps with the three children's school fees. During our visit, the Government had just announced that school fees were going to be increased by 1000% starting the new year of January 2006. She stated that she didn't think that the children were going to continue with their education for the brother was struggling to pay the old fees.

The family cannot afford to purchase maize meal so they had to beg from relatives in other villages. Food for work was now scarce because many people were after the jobs. The young girls had to climb huge trees to get wild okra leaves (mbuyubuyu), pound these and cook them as a relish. The area of Furunga has salty water. The villagers use this for drinking as well as cooking and washing. They cannot have gardens because the water kills the plants. When cooking they do not use salt because there is enough salt in the water. The children presented with yellow corroded teeth due to the water and apparently the water stains white clothes. The researcher drank a little bit and did not enjoy the water. The mother does not see any future for the child because he is not mobile and his epilepsy is not well controlled. Peter has learning disabilities as well.

Just after the researcher finished her study, the assistant reported that two of the children involved in the study had died and that Peter was one of them. Apparently, Peter had a grandmal fit, was unconscious and later died at home. Due to financial constraints, the family never managed to get to the hospital for their son's treatment. There was no money to pay for transport to the hospital as well as the hospital fee. There were neither cows nor a cart to take him to the hospital. Peter died, just like many other children of Binga.

#### **4.1.4 - Discussion of cases**

The researcher had no previous experience in participant observation. I had to learn 'how to do field research by doing field research (Bailey, 1996). I am glad to report that it was the best part of my study for I managed to pick up additional, detailed and interesting information. This also helped to clarify some information I had picked up during interviews. Participant observation is the part where I had a good laugh despite all the constraints like sleeping in the open air and its problems.

The above three cases inform the study and validate some phenomenon which had been discussed in the introduction.

The three families had children with disabilities (cerebral palsy) and lived in adjacent villages. All the three children were born at home. According to the parents this was due to the families not affording the hospital fees. One wonders whether or not this would have happened if the three mothers had given birth in a hospital with a doctor. The researcher is not saying that traditional birth attendants are incompetent but just that they cannot manage complications. On the other hand, I am not saying that this cannot happen in a hospital but just that one should be able to have a choice between the hospital and traditional birth attendant.

According to the parents disability in all the three cases was due to witchcraft but still one wonders whether this could also not be a case of people blaming each other due to their life situation of abject poverty for example 'the haves and have nots'.

In Joe's case, the family's main problem like everyone else was food scarcity. The grandmother weaves baskets and sells these to other villagers in exchange for chickens, food or cash. She then uses the money to buy sorghum so as to feed the family. They are one of the lucky families who still own a few goats and chickens. These give them milk as well as selling them for cash or sorghum. The grandfather stated that they did not get much milk from the goats due to the persisting droughts and lack of green vegetation for them to feed on. Most of the goats were very thin as the researcher noted when we occasionally bought the meat for consumption. This was one area where the 'Newcastle' disease had not wiped out the chickens.

The family are also lucky because they live in a village that has a small irrigation scheme whereby a few villagers who can afford it bought into it and grow crops all year round. Each family owns a few strips of land, pay for the water and grow crops like beans, maize, wheat and sweet potatoes. Unfortunately these families do not have a lot of surplus food so they only sell a little to other villagers. Joe's grandparents cannot afford to join the scheme so they buy the food when they can afford it. The researcher visited the irrigation and found that it was considered women's work. When the researcher asked the women why the men did not work with them, they stated that men are just lazy and do not want to be working all year round; as a result they only work in the fields and not the irrigation.

There is a nearby mission school and hospital so this makes life easier for them when Joe is not well (only take him to the hospital when they can afford it, and not all the time). When Joe's grandmother's brother used to work in Bulawayo, (until 2 years ago), he did help once with purchasing special shoes for him. Now that he has been made redundant, Joe has no one to help with this problem. Otherwise the grandmother stated that with the food problem, they are lucky compared to the others who may go for a day or so without. However she stated that they do not have as much in their plates as before, and tend to eat mainly in the evenings.

Joe and his grandparents are struggling but not as bad as Annie and Peter's mothers. In Joe's case, there is a network of the extended family that helps with caring for Joe when needed. Ingstad, (1988) called it the '*household's labour capacity*'. In this case the care is seen to be given by the aunties and this helps the family with coping with care for Joe. Although worried about leaving him behind when she has to carry out household chores, the grandmother can still manage to get help from the extended family. The researcher noted from participant observation that the family seemed to be a close knit one. The grandmother told us that at times the young girls do fetch water for her. On the other hand, the grandparents seemed to be experienced in that they have met many life challenges and dealt with them and now seem to take life as it comes. Joe's grandmother also stated that she liked taking care of Joe since this was their culture of looking after grandchildren. She once stated, '*one would not feel like a grandmother if one did not have a grandchild in the home*'.

Annie's mother on the other hand is finding life increasingly difficult to cope with her daughter and life in general. She has to rely on her sister in law for food and support. The sister in law has also got two children to cope with as well as her in-laws, i.e. Annie's grandparents. They live in the mountains (Chizarire range) whereby they share their crops with elephants leading to hunger every year. Water is also very far from the village and women have to spend a lot of their time fetching water for the family. Most of them reported chest and back pains after carrying buckets of water for long journeys.

These families rely on poaching in order to survive. They utilise the meat as well as sell it for grain like sorghum or for cash. [There is a danger of being caught and a prison sentence] The villagers have to survive as a result they have no other alternative but to poach. In her case, the family are worse off because there is no man in the family to go poaching with the other

men of the village. They have to purchase the meat. Her father is very old and does not go out hunting anymore. This creates more constraints for the family when there is lack of food in the house.

Annie's mother stated that she used to weave Tonga baskets and sell them to passing tourists. Due to the country's economic decline and political situation, there are virtually no tourists visiting the area. This has resulted in her not getting cash to purchase soap, and other essentials. She also used to do a lot of 'food for work' on other villagers homes, but has had to cut down due to Annie's numerous hospitalisations. This situation has led her to be depressed and not managing with coping with care for Annie. She stated how she gets helpless especially when she has no cash to take Annie to the hospital. The whole family, including the brother's family survives on the money that he sends from his workplace to purchase maize and other grains.

The researcher noted that being young and inexperienced; Annie's mother was increasingly finding it difficult to cope with caring for her daughter. The sister in law is also young but has two healthy children which Annie's mother kept comparing with Annie. This did not help the situation. This has been noted to be common among families with disabled children whereby they compare their situation with families without disabled children. The grandmother does help when she can although she too stated that she had a field to attend to during the rainy season.

In the case of Peter the family live from hand to mouth just like Annie's family. The mother stated that they have days when the family do not have enough to eat for the day and wait until they get more food in the house. It was a common site to see women and girls climbing up huge trees to get to the green leaves (wild okra) so as to cook and eat for the evening meal. When they cannot afford maize meal, the villagers have been known to cook and drink the stuff on its own without the traditional maize meal porridge (sadza).

As if lack of water is not enough problems, the people of Furunga (Peter) have got salty water to contend with. The children were seen to have yellow corroded teeth. The researcher discussed the issue with a dentist who stated that it was the water and it needed treating. Apparently this is an expensive exercise so the best solution was for the government to get water from the Zambezi to these villages. The rest of the district needs piped water for as

noted, the other two families have drinking water problems as well. Botswana a neighbouring country provides piped water to the villages and one wonders why the same system cannot be applied for the Tonga.

The researcher noted that Peter's mother has lived in a '*disabled family*' (Ingstad, 1988) since she was born. She stated that as a young girl, she grew up helping her mother take care of her older sister who is disabled. As a result she just continued after their mother's death because she did not move away from their parent's homestead. She now had to look after her six children as well as the sister and her daughter. As a result of all this, she saw her life situation as being the same, i.e. before having Peter and after discovering the disability. She saw herself as having been poor and still poor, if not poorer.

The researcher found that her main constraints on coping with care for Peter were economic. This was noted when she stated that the family could not even afford to buy candles to use at night. It was also sad to hear that Peter occasionally has fits at night and the mother will not have a candle to light and comfort him. She stated, '*It all happens in the dark and I just hold him afterwards*'. The researcher had to take candles to Zimbabwe from Oslo incase they were not available in the shops in Harare (shortages of commodities in shops) these were used during participant observation.

I found this frightening because snakes are quite common during the rainy season, i.e. they can get into the houses at night and people have been known to be bitten and die if it is a poisonous snake. Lack of money also meant that Peter could not get his epileptic medication. The mother told us that this was one of the most stressful situations she has had to live with. During our visit, her latest problem was her children not managing to continue with their education. The government had just announced an increase in school fees beginning January 2006. As a researcher, one could see that past experiences and personality factors, kept her 'going', i.e. helped her with coping with her disabled child and sister.

The three mothers stated that they could not afford the hospital fees then, and this is still the same situation. Infections come and go without hospital treatments at times. Annie is so malnourished that one cannot see her surviving for long. Joe suffers from headaches that put him to bed for a few days a month and he is not able to walk for long distances. Peter is suffering multiple fits due to lack of medication. This has led to the popularity of medical

pluralism among the villagers due to financial constraints. This can be detrimental to a child's health for instance in Peter's case of epilepsy. The parents had tried anti-epileptic medication (biomedicine) and it worked but they were now unable to go back to the hospital. Malaria was also a problem that needed hospital treatment. The three families stated that during such times, money had to be found otherwise one loses the child.

The aim of the thesis has been to ascertain coping behaviours of families with disabled children. The three cases help to bring out a picture of the life of the Tonga in general. The major factor within the community is poverty, manifested by their need for basic food. Lack of food has been noted to cause malnutrition which in turn can result in diseases and eventual death. Coping in such an environment is made difficult because the families are not managing to meet the changes that take place in the household when a disabled child is born. The paper has already pointed out the changes that have taken place in the families' everyday lives due to having a disabled child e.g. having less time to attend to the fields due to hospital or traditional healers' visits. Such a situation makes a poor family poorer.

In Annie and Peter's mothers' cases, the changes that take place can be seen as making them poorer and more stressed to cope with looking after their disabled children. They both now have to spend a lot of time looking after their children who are ill most of the time and spending less time in their fields as well as basket weaving that they used to do to earn money. They are now unable to do '*food for work*' like the other women in the villages. These changes are seen to create changes in the opportunity situation resulting in constraints under which choices are made. The results of these changes are seen to be making the families poorer, more stressed and not able to cope with care for their children.

In most of the cases, the researcher noted that the families were struggling to cope with their disabled children. Socio-economic circumstances were against them. Poverty was the first thing the researcher noted on entering the villages. There was a gross lack of food in almost all the households visited. Maize meal or sorghum which is a staple food was scarce due to government not supplying the grain (which was for sale) as well as stopping the NGO community from entering the district and giving out food (for free) to the people. In this case the Tonga were denied purchasing, (if they could afford it) as well as free maize-meal. The prices on the maize meal in the village shops were more than double that in the cities; with the retailers citing black market fuel prices and that it was a scarce commodity at times (gold).

The researcher noted that in some shops the retailers opened the bags and sold the maize-meal in small amounts so that people could afford to buy so as to have something to eat for that day. The retailers were making a huge profit with such a scheme. This was sad to note. Clothes were their second need. They had been buying old clothes from women from Bulawayo in exchange for chickens, baskets and a popular wild sour fruit (busika) that people put in porridge to make it sour and palatable.

Lack of support from the government is their biggest problem. As noted before, their school services are far too short to service the whole district. The district is sparsely populated therefore there is a need to reorganise the infrastructure so as more children get access to schools. Having visited Annie's mother and the nearest school (8kms away), I cannot see her daughter attaining any education at all, that is if she survives the continuous infections she gets. On the other hand, Joe and Peter will need a wheelchair and attendant if they have to get to the nearest school and back. This shows that children with disabilities in the district will still continue to be excluded from education which they need most in order not to continue being poor citizens. Here, we can see poverty and disability rearing its ugly head.

Unlike the other villages inland, we had to sleep inside because of elephants that pass through the villages at night looking for food (spoiling my bit of adventure). I gathered that other wild animals like hyenas, jackals and sometimes lions visit the homesteads at night and kill the families' goats for food. So, despite the high temperatures at night, the villagers have to sleep inside their homes for safety. The researcher also noted that the high temperatures did not help either when the children had fever because this exacerbated the illness. It was in such instances that one noticed the helplessness of the mothers towards their sick children. There was no aspirin or cold water for tepid sponging to help take the temperature down (drinking water was a bit warm most of the time). It is factors like these that influence coping.

With all these problems noted, the researcher did enquire whether or not the mothers, in frustration, did abuse their disabled children in any form e.g. beating them up, withdrawing of food or verbal abuse. Annie's mother stated that she did get annoyed with Annie at times especially when she passed stools in her pants. I then retorted that children of Annie's age do that at times. She then stated; *'I know. The problem is that most of the time, we go without soap, so I have to just shake the stools out, dip the pants in water and dry them out again.'*



*This is not right*'. I nearly got emotionally caught but quickly pulled myself together. I was not to get involved. Annie had two admissions to the district hospital during the study. The team helped with basics like soap, vaseline and cordials whilst she was on the ward.

Modern health care services are the worst services provided by the government in the district. For a start there is a shortage of manpower due to the 'brain drain' that has been taking place in the country for the past seven years or so. For those still in the country, most professionals do not like working out in the countryside where there is no electricity and running water. The lack of doctors and nurses, as stated before has resulted in high maternal and child mortality rates in the district. In the case of Annie, Joe and Peter we can see that hospital fees and transport to the hospital has now become inaccessible to most of the villagers. Just last month, i.e. April 2006 – the government announced an increase in hospital fees. In district hospitals like Binga, the fee went up from USD 0.12 to USD 1.5.

In all the three cases we notice that the families can only take the children to the hospital if and when the family get the money otherwise at times, the child gets sick and gets better with home treatments and in some cases this may mean death at home. If the families could not afford the USD 0.12 how on earth are they going to manage the new hospital fees? Many more children are going to die as well as get disabilities in the villages. The lack of free vaccines (during the study) was another issue that sent alarm bells ringing. This meant a death sentence to some of the village children. Joe on the other hand needs special shoes to enable him to walk with ease but the family cannot afford it. He has to continue watching his friends walk far away from home herding goats and enjoying themselves. He may have to endure the pain of watching his friends going to school in the future. Surely this is not Joe's grandparent's fault; it is the fault of a government that has failed to do its duty to its people.

Lack of resources like access to safe drinking water for people and animals is a problem noted in the three cases as well as the rest of the district. As stated before, the Tonga are still *'waiting for their water to follow them'*. In the case of Annie's mother, I had the privilege of waking up at 0430hrs and walking for two hours one way to fetch water. In Joe's grandmother's case, it was a short walk to the dry river bed (20 minutes walk) where the women dig a hole in the sand, wait for the water to raise and then fetch it. In Peter's case, it is a life of drinking salty water. I was told that at times they get cholera outbreaks in the district. Lack of water also saw the death of domestic animals like cows. If only the government

would get water to the people as well as their animals, lives could be improved. The villagers would have their animals and have milk and meat to eat.

Apart from seeing children with disabilities for my study, I also had the privilege of visiting the district hospital on several occasions where I saw severely malnourished children suffering from different infections. They were too weak to lift their heads and crying from pain. One two month old baby had been admitted with its grandmother because its mother had died from HIV \ AIDS. After two weeks of feeding on the nutritious porridge on the ward, the grandmother will take the baby home. After discharge, they were not allowed to take home a bag of porridge. My question to this was; *'What is she (grandmother) going to do when she gets home?'* The answer from the authorities was; *'We are not allowed to give out the porridge meal to take home'*. The baby was wearing an old, torn, dirty dress the size of a two year old. I asked the grandmother why she dressed up the baby in such a big dress and she stated that one of the neighbours had given the baby the dress. Such problems, as well as the plight of children with disabilities make one think that the children of Binga are paying for their country's politics. How can parents be seen to be coping in such a situation?

Tonga ethno medical beliefs are one of the variables that help them cope with care of their children with disabilities for they believe that disability is a result of witchcraft meaning that no one in the immediate family is to blame for the disability. Attitudes have also been shown to help to a certain extent in that they cannot be said to be fully responsible for coping. In the three cases life experiences and personality factors have been seen to play a part in coping.

The results of the case studies generally show the widespread poverty and lack of resources for the families. They show how a government has abandoned a community and rendered it helpless. Without basic everyday necessities like food, soap, candles etc. one cannot be expected to cope, let alone a family with a disabled child who is always ill and needs both physical and medical attention.

One interesting phenomenon that the researcher found was the fact that these families loved their children. To most of the mothers, having a child with disabilities was *'one of those things that happen in life'* just the same as in Ingstad's (1988) Batswana families. To them, it could also be a case of they have had other children die and so having one that is alive is a bonus despite the disability (see the Tonga proverb in the next section). The suffering of the

child with disabilities has been noted to extend to the rest of the family, e.g. when money is used as hospital fees whilst the rest of the family go without. This makes coping very difficult.

## **4.2 The Concept of misfortune among the Tonga**

The findings of the study have been put under headings, though there are many cross cutting issues and responses, whose presentation and discussion is overlapping, just like the subject of investigation itself.

***‘Kocilema kunywigwa maanzi’***. This is a Tonga proverb meaning that ***‘It is better to be disabled than death’***.

The Tonga mostly believe the causes of disability to be witchcraft (kuroyiwa) ancestor’s sorrow or anger (mizimu) and the will of God, natural reasons, or ‘just happened’. The first two causes could be termed *‘Tonga diseases’* as they have a Tonga name and can be identified as originating in disturbed social relations (personalistic theory). When no traditional explanation is found, the cause of disability is seen as God’s will (natural reasons) or *‘it just happened’*.

### **4.2.1 Witchcraft**

plays an important part in most Tonga activities for example, if one sustains a snake bite whilst walking through the forest, this can be explained as witchcraft - by a jealous neighbour or relative. Evans-Pritchard, (1989) from his study of the Azande; found that ‘the concept of witchcraft provides them with a natural philosophy by which the relations between men and unfortunate events are explained. Witchcraft beliefs also embrace a system of values which regulate human conduct towards each other and enforce culturally prescribed obligations and rules of social behaviour (Ingstad, 1997).

In the case of the ‘snake-bite’ incident this could be a retaliation of what took place before among the two families e.g. exchange of bad words; a socially relevant cause since it is the only one which allows intervention and determines social behaviour. It also gives an opening for conflict solving. The affected family can then decide to seek treatment and retaliate or

make peace. The negative side of this is that it is a social stressor in that it increases tensions in close relationships etc.

When the question of the cause of their child's disability was posed, all the participants stated that it was witchcraft. Annie's mother stated; *'My child was bewitched by my husband's 2<sup>nd</sup> wife. When I was pregnant I asked my husband if he could buy me a baby towel so as to carry the baby on my back after giving birth. My husband said he did not have money then but would see if he could find some. To this my co-wife asked why I should ask for a towel when the baby was not even born. How do I know that I will have the baby? I did not understand this and so I kept quiet. The home birth was a difficult one; the baby had a cord round her neck and did not cry until the following day. At four months the baby could not sit unaided, had no head control, drooled all the time and had a bent neck. My husband and I took the baby to the traditional healer and we were told that she had been bewitched'*.

The researcher found that this was a common phenomenon among the polygamous families. Witchcraft accusations were common between people who were competing for the love of the same person. Tonga men marry additional wives for various reasons like; Tonga women when they are no longer able to bear children often abandon their husbands to settle with their married children and this leaves the old husband on his own and not able to marry - therefore they say it is better to keep marrying when you are young. This way enables the man to hope that at least one wife will stay.

Joe's grandmother stated the cause of disability on her grandson as jealous neighbours. When asked to explain this she stated, *'My daughter was bewitched by one of the neighbours because my family have a large herd of cattle. The aim here was to get my daughter divorced by her husband due to having a child with disabilities'*. The girl did get divorced by her husband and left the one year old baby with her parents to get married to another man. During participant observation, she did arrive at the homestead with her two young children from the 2<sup>nd</sup> marriage after being divorced again. She had been married for three years. Joe's grandmother (this time) stated; *'munyama wangu'* meaning *'I am just unlucky'*.

The researcher noted that it was common for families to accuse each other of bewitching the child. The wives parents were the most accused as well as co – wives. One husband simply stated, *'There is nothing like this in my family'*. I could detect the bewilderment in the mother

of the child. In some cases the blame was put on either the father in law or the mother in law for not wanting the two to get married. One family reported that the husband's family had taken the little boy's soul and used it for witchcraft (chikwambo); a common phenomenon in Zimbabwe whereby a family gets riches through acquiring someone's body or soul. This 'being' is the one that takes money from different places or people undetected and take it back to its master. The little boy could not talk and was microcephalic. Others reported that a family member had murdered someone years ago, and so this was revenge from the dead person's spirit. In such cases, the family is asked to pay cows or pay by sending a young girl to the family of the deceased. This girl is then married to one of the deceased's relative.

#### **4.2.2 Ancestors' sorrow or anger**

with the family. The participants stated that this happens for example in cases of an unsuccessful abortion. Their explanation is that ancestors do not like abortions and see the practice as an 'evil act'. The punishment of the act is that one gives birth to a child with disabilities. Colson, (1958) states that '*The Tonga assumes that it is natural to desire children---it is good to bear children---the birth of children provides a new insurance to a marriage*'. They also believe that it is possible to have legitimate children without entering into marriage although they feel that it is best for a child to be born and reared in a household formed by its parents. The researcher also noted that they desire many children, as seen in the households during the study (e.g. a family could have 30 children or more). Colson further states that the Tonga desire many children for they see in this the only way of offsetting the high child mortality; and that children are of assistance to the work of a household from an early age rather than a burden upon it.

The cause of disability as ancestor's sorrow or anger due to abortion can be seen as symbolic. It could be interpreted that abortion is a practise that should not be encouraged among the community. As a result if one commits the act, the result would be one having a disabled child in the future.

The high child mortality rate is still evident as noted by the researcher due to the poverty and lack of resources that has always dogged the Tonga. This and their desire for many children may mean that the phenomenon of abortions causing children's disability could be symbolic.

Ancestral sorrow or anger is also manifested when the family has angered the ancestors (mizimu) by not brewing beer for them. The Tonga are constantly making offerings to the ancestral spirits. These are the regular offerings made by all adult men and women whether they are involved in any misfortune or not. They have been taught that on certain occasions offerings must be made, and they have learnt the names of the mizimu which they must call. For example, changes in the location of a household must be announced to the mizimu by offerings made before leaving the old dwelling and soon after entering into the new one. This also includes change in status, the initiation of some activity and its successful completion and other activities.

The family gather together in the evening or early morning and take the sorghum to be used and call on their ancestors (mizimu) and say why they are preparing the beer. The beer is then prepared for seven days before it is ready to drink. On the day of the drinking session, the family will again call on the mizimu and offer them some of the beer. This is done by pouring some of the beer into the ground in one of the huts or wherever the traditional healer deems suitable. The rest of the beer can then be utilised by the invited guests and family.

One of the participants in Colson's study stated; *'Even if everything is going well with me, I should still make an offering for the mizimu to tell them that I am alright and that I want to continue to be alright and that they should help me just as they have been doing'*. She continues to state that the mizimu are also important in another sphere, as causal explanations evoked to account for illness or other misfortune which has befallen some individual. According to the participants, the traditional healer announces that one's mizimu is angry because it has been neglected. Either it has not been called when offerings have been made, or the offender has been dilatory in making offerings. The remedy is a special offering at which the offended mizimu is invoked by name and assured that it will henceforth be remembered.

The anger and sorrow of the mizimu was explained as above by some of the participants who reported this as the cause of their children's disabilities. When the researcher further probed the participants about the large number of children with disabilities noted, their explanation was that the extreme poverty had brought on all their suffering because they were now unable to cultivate enough or buy sorghum to brew beer to thank their ancestors. Most of them stated that they now had to invoke the ancestors and ask for forgiveness for not brewing them beer

and promise that they will do so when they get the sorghum. This according to Colson shows how social structure and the cult of the mizimu are so intertwined among the Tonga.

#### **4.2.3 The will of God, natural reasons, or ‘just happened’**

This is when all the preceding possibilities for explaining a medical condition or other types of misfortune have been considered and one still remains without an answer. In such cases it is said to be ‘*God’s will,*’ ‘*caused by natural reasons,*’ *it ‘just happened’ or it is ‘just a disease’* Like the Tswana medical system, (Ingstad, 1988) there is clearly a need for a ‘remainder category’ to which unexplained or difficult cases may be referred.

In this study, two participants’ extended family members (aunties) mentioned the cause of disability as ‘*a natural thing whereby no one should be blamed for the cause*’. Another one reported that she was ‘*just unlucky*’ (munyama wangu). In her study of causes of disabilities in Zimbabwe, (Burck, 1989) reported these to be natural and cultural. In this study, the few that had first indicated that the cause was natural changed to cultural later on during the interview or during participant observation; making all participants reporting cultural causes as the cause of disability. It would be interesting to revisit the two ‘aunties’ again and see whether or not they still stood by their belief of a natural cause.

The Tonga’s belief in cultural causes of disability makes them invoke ‘personalistic’ causes. According to (Foster, 1989) personalistic explanations extend to the domains of social relations – living with people, ancestors and other spiritual entities. Therefore personalistic cures must not deal with immediate causes for an illness (like witchcraft) but also the underlying social rifts that have provoked the witchcraft (discussed later in the study).

A good example of personalistic aetiology is the Zimbabwean notion that ‘death is unnatural’. The immediate family has to consult a traditional healer to ascertain the cause of death (this includes death from HIV/AIDS). Like Foster, they believe that ‘*People sicken and die because some power, good or evil, has acted against them*’.

On the basis of the Tonga causes of disability, one can conclude that the Tonga medical model is a way of thinking in which causation is defined at several levels with the ultimate origin of misfortune being rooted in disturbed relationships between the affected person and

his ancestors, relatives and friends \ neighbours, or the will of God. It is also important to point out that there is no victim blaming of the mother for the cause of the child's disability. This may make coping not so stressful for the family especially the mother. In the case of breaking a taboo, an explanation in the form of an 'exploratory model' is considered so that no one gets the blame.

### **4.3 - Choice of family treatment**

Kleinman (1978:422 cited in Helman 2001) suggested that in looking at any society, one can identify three overlapping and interconnected sectors of health care; the 'popular' sector, the 'folk' sector and the 'professional' sector. The popular sector is all the therapy options that people utilise whilst paying and consulting either folk healers or medical practitioners. This also includes self medication or treatment advice from friends, relatives or neighbours. The folk sector is where certain individuals specialise in forms of healing that are either sacred or secular or a mixture of the two. The professional sector is biomedicine.

As noted before, Tonga ethno medicine is not a 'closed' system. The traditional healer is the first port of call for most families. In the case of this study the family first consults the popular sector in order to ascertain the cause of the disability. A few families reported to be using the folk sector as well as biomedicine.

All the participants stated that the family gets involved in the treatment of the child, especially going to the traditional healer. However, the female participants stated that when it came to decisions of taking the child to the hospital or church, most men did not participate in this. When the men were asked why they did this, they stated that they were satisfied with the traditional healer and that the child could not be helped anyway by other means. They also stated that it was good for the women to get moral support from each other since they are the ones that look after the children. Being a matrilineal society, Tonga men are not so much involved with their children, and maybe this could explain why the women need outside support.



#### 4.4 - In Search of a Cause

In the event of having a disabled child, the family would first visit the traditional healer (n'anga), who can either be a man or woman. This can be the local one or in other villages. This depends on how 'good' the traditional healer is, according to friends and family. The popular healers were the ones that were known to have travelled outside the country so as to acquire new knowledge and medicines. The belief is that these are 'stronger'. The Tonga stated that a good n'anga is one that had visited either Malawi or Mozambique for further training and acquisition of medicines. This shows that the ethno medical system must not be seen as a closed system unaffected by other influences. A popularly visited n'anga was Tsikamutanda, who was known to have great healing powers.

The visit to the traditional healer is very important for them because this is where the cause of disability is explained to the family. This is very crucial to them because knowing the cause will lead to the family 'making right' what it is that will have caused the disability and the child is not blamed for being disabled. The researcher found quite a contrast in the way the Tonga perceived their disabled children; as compared to Scheper- Hughes (1992) poor Alto mothers of Brazil. The Alto mothers perceived disabled as well as weak children to have decided (after birth) that they are going to die. As a result, they withdraw nourishment as well as care so as to let them die. The Alto babies are not perceived to be 'persons'. In the case of the Tonga, the individual's humanity is in no doubt; unlike Scheper-Hughes (1992) *'poor little critters'* all excluded from the realm of humanity.

The Tonga did not see their children with disabilities as the Alto mothers did, i.e. that *'if a baby wants to die, it will die---it was wrong to fight death'*; their beliefs about sour or insufficient breast milk etc and patterns of enculturation that routinize infant death. The researcher found among the Tonga, a kind of *'natural integration'* of these disabled children in the sense that they did their best to look after them without reservations. If the child died, it was a result of not having enough food and lack of health care.

According to the parents who had already visited the traditional healer, he or she would make some razor cuts on the child's body and apply well ground burnt herbs into the cuts. The parents will also be advised to burn the wild herbs while the child is covered in a blanket. They believe the smoke might drive off the angry spirits that will have caused the disability.

They will also be herbs to put into the child's bath water and to drink as well as inhalation. The prescribed way depends on the cause and type of illness, and varies considerably between the n'angas – even for the same problem.

The parents will then advise the headman as well as the community after visiting the traditional healer. The community would then organise a ritual. The headman then calls the parents of the disabled child and advises them to brew beer for the ancestral spirits as a way of appeasing the angry spirits. The community will beat drums and sing ancestral songs – praising the ancestors. They believe this would please the spirits and the child will be healed. The community would then take the disabled child to the headman for better care, where they would also take food and herbs to help. This continues for a length of time until a decision is made for the parents to take the child home.

If this is seen not to work, nowadays some young parents take the disabled child to the prophets (maporofita). This seems mainly to be done by younger parents who are turning to the so called 'new churches' (Zionist and Pentecostal) for help. The prophet uses 'blessed water' and prayer only. The parents would be given this blessed water to take home for the baby to drink as well as to bath in. It was common to see babies with threads of blue, red and white tied round their necks, wrists, ankles and waists. These would have been prayed for by the prophet and their purpose is to aid in healing.

The researcher noted that older parents, ie thirty years and above were not into the Christian religions. They just stated, '*we are not interested*'. One reason could be that prophets discourage their followers from visiting the n'angas. The other group, members of European Christian Churches like Catholics, Methodists and Protestants would take the child to the district hospital (Rehabilitation Department) if they can afford it.

However, nowadays the Tonga do not follow the whole procedure. The family visit the traditional healer and then carry out whatever rituals they have to as a family. The headman and chief are in most cases advised of the rituals, e.g. when the family has to brew beer etc.

Unlike people in other parts of Zimbabwe where one can find that a higher proportion of the population with no formal education chose to go to traditional healers compared to the groups with some formal education; the situation among the Tonga is different. This is so because

most of them have a little or no education at all. As a result this is accepted by the community. However, even educated people all over Zimbabwe are now seen to be visiting traditional healers in the dark of the night so as not to be seen to be doing so. According to the Zimbabwe National Traditional Healers Association (ZINATHA) president; Professor Chavhunduka, this is due to our rapidly declining economy in the country. People now visit the traditional healers so as to 'strengthen' themselves so as not to lose their jobs or to get 'good luck' charms etc.

The researcher had opportunities to attend both the conventional and new churches; and noted the charisma in the later. There was the preaching, singing and praying out loud so as to invoke the 'holy spirit'. The result is that of the congregation 'speaking in tongues'. This alone would lead a parent to believe that their child can be healed or other comforting thoughts. The researcher noted that these are villagers who may have lost faith in the ancestors (mizimu) and were now resorting to other incoming or modern 'faiths' for help with their disabled children and other misfortunes.

The Zimbabwean; (06-02-2006) *'It has been noted that church attendance is up in countries experiencing economic difficulty and political uncertainty.'* I had the opportunity to talk to a mother of a seventeen year old daughter who had learning difficulties. The mother stated that she had been through the whole process, but realised that nothing will work but a miracle from God.

The above information shows the importance of the cause of disability to the families. The families have to do this first before they seek treatment from the traditional healer or the hospital later. There is also the issue that no one gets to be blamed for the child's disability because this would have been witchcraft according to the traditional healer. More importantly, the mother does not blame herself. This situation is unlike the Western notion that the first port of call would be rehabilitation for the disabled child. There is also the possibility that a mother can blame herself for the disability by citing her age, e.g. if she has the baby late in life or blame herself for smoking whilst pregnant. The father can also do the same if he thinks that he is to blame in some way. Therefore, the Tonga personalistic theory as well as explanatory models helps them to a certain extent cope with their disabled children.

The above information shows the importance of the cause of the child's disability. One notes that as soon as the cause of disability is found, treatment then follows. After this, the family settles down, gets on with their lives and takes care of the disabled child.

#### **4.5 - Community Attitudes**

The International Year of Disabled Persons (1981) and the following decade dedicated to the same (1983 – 1992) were intended to draw attention to the situation of disabled people worldwide. As with previous years and decades named for other purposes (women, children, water, etc.), one can hardly note any revolutionary changes in the life situation of disabled people in most places, but perhaps there is an increased awareness about the needs of this underprivileged group of the population, especially in the so called third world countries (Ingstad, B.1995). Most developing countries rely heavily on foreign donor agencies and non-governmental agencies (NGOs) as well as local fund raising in their rehabilitation efforts due to the general shortage of resources. Little emphasis is placed on poverty, limitation of health care and so on; but on attitudes, and especially the attitudes of the caretaker leading to the '*myth of the hidden disabled*' (Ingstad, 1991). This became one of the researcher's phenomenons to be looked into.

In their study of Norwegian families with disabled children (Ingstad and Sommerschild 1984) in which they focussed on the coping ability of such families, it was demonstrated that life circumstances played a much more significant role than the attitudes of the parents in determining coping. Seeing that I had a small sample and less time in the field, I did not come across any cases of parents hiding or abusing their disabled children. In my case I had to ask my assistant whether she had heard of any such cases in the community. This is when she came up with the story below.

##### **4.5.1 - A Case of 'Hiding'**

During the course of my fieldwork I established a very good relationship with my research assistant, a rehabilitation technician who worked full time at the district hospital. I shared her house together with her family when we were not out in the villages. One day I started asking her about any cases of 'hiding' or 'neglect' that she had come across in her twenty years of

working in the district. She stated that there had been no such cases but a case where the family did not know what to do with their disabled child.

Apparently this took place in the mountains where this family had moved to in search of new pastures and fields. This family lived more or less on their own, away from the other villagers and relatives. The woman had a difficult and prolonged home birth which led to the child having disabilities. According to the other villagers, she would not bring the child out in the homestead but kept the child in the hut all the time. In other words no one saw the child and the villagers started to talk amongst themselves saying that maybe the mother was abusing the child or mistreating it. This went on for nearly a year until the rehabilitation team visited the village during a census. This was reported to them and when the woman was asked about her baby, she stated that she didn't have a baby.

The team left the village when their work was done. Another report came to the hospital saying that someone had seen the baby when they were passing through the homestead. The rehabilitation technician and a nurse visited the woman who broke down and admitted that she did have a baby. When the baby was brought outside, apparently it was 'white' and was not able to tolerate light and could not sit up. The mother's explanation was that she did not know what to do with the child but had been breast feeding and looking after the child well.

It was then explained to the mother that the child was disabled and that there was no need to keep him in the hut all the time. The team then showed her how to handle the child and visited a few times to support the family.

One can see from the above case that at first glance, it seems like a case of 'hiding' the disabled child and yet there are practical explanations. When looked into more closely, one finds that it reveals a story of love and concern. This was a case of lack of knowledge on the mother as well as lack of support from the family left behind. But most of all, there was the lack of resources like money to take the child to the nearest clinic or hospital and to pay for the hospital fees. This is what poverty can do to a community. The child was not being hidden away. Victim blaming can easily be bestowed on the mother of the child for 'hiding' the child and yet this should not be the case.

This story shows us the danger of prejudging the situation of a family with a disabled child without full consideration of all the facts. Looking at cases by Ingstad, (1991) she states that *'Good judgement must be based on thorough knowledge of how family members see their own situation and an understanding of the possibilities and constraints under which their choices of action are made'*.

#### **4.6 - The concept of Attitudes**

There have been many definitions of attitudes and yet none of them suggests that attitudes may vary with the social situation in which they are acted out. They are socially as well as culturally constructed and dynamic in character. Ingstad, (1997) suggests that attitude be defined as *'a statement about disposition to act toward a person, group or object'*. She continues to state that perhaps in this way we may avoid the danger of confusing statements with action, and the tendency to conclude that the life situation of disabled people in the community is the result of a single cause and effect.

When asked about the community attitudes towards their children, most parents gave positive comments whilst a few gave negative ones. A young mother stated, *'bayangizwela---life emakhaya inzima sibili'*. This means that the community *'feels pity for me---life in the villages is very tough'*. The majority stated that the community was *'kind and sympathetic---the community still respects us and treat us as before'*.

One grandmother looking after her grandson stated; *'The community do not comment on the child's disability. They just look – The community just looks and do not say anything – People just look and feel sorry for the child – God created the child, so people should not look down on him – The child is from God and so the parents should take care of their 'gift'*.

The negative attitudes were given as; comments about the child, for example a reference to the child not being able to walk, (mwana mutela). They stated that people did not express any fright towards the children. One young woman cited an incident where her father in law mentioned that the disability came from her side of the family and not his (a high ranking officer). The child was nearly two years old and still unable to sit independently. One young mother stated that one of her younger sisters avoided her child. She could not help by looking

after the child when she needed to perform household chores. *'I have to take the child with me to the borehole because she will not take care of the child'*.

Teasing and laughing was reported as coming from the women's kinsmen, i.e. their *'bamutala'*. This act is allowed and is not meant to be hurtful. In this case the women make disability jokes about their relative's child with disabilities. The belief is that such an act helps the mother cope with the child's disability when people talk about it.

The parents' attitudes towards their children differed from each other. The researcher noted that the parents, whose children had some degree of mobility, saw their children as future helpers at home and useful members of the community. This is important to the Tonga since the labour of children is essential for the ordinary domestic work of a household (girls) and boys for the herding of cattle. *'He has been our only grandchild for the past four years, now he manages to walk a little and helps with milking the goats. He helps a little in the house and he is great company'*. The parents whose children did not have any form of mobility stated that they did not think that their children would become useful family or community members. *'I do not see any future for the child. I see a future filled with problems all the time. She is not independent in anyway'*.

The researcher noted that the participants reported positive attitudes towards children with physical disability and sensory impairments compared to negative attitudes shown towards children with 'strange behaviour' and learning disabilities. Negative attitudes were reported by three families of children with behavioural problems, learning disabilities and epilepsy. The child with behavioural problems had a tendency to use foul language and was aggressive at times; and this induced fear of uncontrolled violence. The mother of the epileptic child reported that it was mainly strangers who were not comfortable with the child but not relatives or neighbours. Negative feelings were shown towards the child with learning disabilities.

One of the mothers had a five year old boy whom she has been tying (wrist) to the pole of the *'ngazi'* (a Tonga hut) since he was two years old. She occasionally unties him when she is at home and can look to see that he does not run off into the woods, river or other dangerous places. She told us that at first the community was indifferent to this act but later realised that it was the best thing to do for her to carry on with her work. She stated that her husband was not helpful at all. The grandmother could not run after him. Her fear was that now he is

getting older, one day he may be able to untie himself and the end result would be death in the river or gorge. She untied the boy during our presence and he was like ‘the wind’ before she caught up with him.

The results show that physical disabilities receive more positive attitudes than various other conditions. This is because most negative reactions are strongly related to ideas about contagiousness (epilepsy), violence (behavioural problems), lack of ability to perform activities of daily living, thus making people with conditions like epilepsy and learning difficulties the most vulnerable.

In conclusion, the researcher agrees that studies of actual behaviour (attitudes) need to be combined with survey questions as well as the social setting in which such behaviour takes place in order not to end up with fairly similar conclusions in most countries such as; disabled people are stigmatized and have poor chances in marriage etc. (Tekle-Haimanot et al.1991). In this study, the Tonga social setting helps with coping with a disabled child in the sense that the researcher noted that the community are close knit and help each other when they can.

The problem of emphasizing attitudes is that one can easily end up with ‘victim blaming’. Poor care of a disabled person is seen as a question of individual attitudes – most often that of the family or caregiver and changes become a question of attitude change. It is important to note that attitudes of professionals or government are rarely questioned.

In many cases, the Tonga included, the difficult circumstances of the families are the result of the difficult life situation of the whole household or care unit. In this case the problem is that of poverty due to scarcity of resources. It may also be lack of support in ‘*a case of hiding*’. This makes coping indeed very difficult. Infact, most families were not coping at all.

#### **4.7 - Life before child with disability was born**

It has been shown that one’s life experience either helps with coping with a situation or it may not help at all. Therefore it becomes important for one to look at life before the incident happened, and in this case it is disability. As a result all the families were asked to describe how life was for them before the child with disabilities was born or before the disability was discovered.



A young 1<sup>st</sup> time mother talked of her life before she discovered that the child was disabled as follows; *'I lived at home with my mother and siblings. I was free to go as I pleased with my friends and do all the household chores. My family is very poor and so I wanted to get married. When I got pregnant, I was happy thinking that the baby's father would marry me and we would stay together, but his father refused and so he did not marry me. I got depressed about this and continued staying home with my mother'*.

The above statement was a common occurrence among the young participants. The researcher noticed that as soon as the child was a year or so old, this young mother would then leave the child with her mother to get married again, becoming the third, fourth or fifth wife at the age of 15 or so. Poverty seemed to be the commonest problem that drives young girls to get pregnant so that they can be looked after by a husband. If they are lucky, they get married again, and on the other hand they may continue having children and asking their mothers to look after them. Saugestad, S. (1990) described how in Zimbabwean villages it is often grandmothers who care for disabled children because parents (or unmarried mothers) are working in town. Some of them leave the villages for work in nearby towns like Bulawayo, Victoria Falls and Hwange. If not, they stay at home with the child until they find another husband.

In one of the cases, Annie's mother stated; *'Life before Annie was born was not so bad. My husband used to do piece jobs and help support the family. I would weave Tonga baskets to sell for cash or exchange for chickens or clothes. The older child was no problem and I could leave him with the neighbours when I had to fetch water or wood'*.

Another young mother stated; *'I was a happy teenager living with my parents at home. They were poor but we managed to live from day to day. I attended school but did not pass any subjects. I used to attend church with friends'*.

One grandmother looking after her grandson stated; *'Before the child's disability was noticed, the family did not have any problems. We could all carry on with whatever work we were doing, visit friends and relatives and attend to the fields and other household chores. My husband and I would go to nearby villages for home made beer in the summer and enjoy the company of our friends and relatives'*.

Ingstad, (1988) states that the process of coping is however greatly influenced by the premises laid down before the disabled child was born. In this case the Tonga socio-cultural setting provides the framework in which the practical as well as the psychological aspects of coping behaviour have their roots. It gives constraints and possibilities for adaptation to an environment characterised by marginal resources, and it gives patterns for how to cope with various critical life events.

The setting also gives standards for 'normality' that is quite different from those encountered in other parts of the country (extreme poverty). The researcher had to look at the families past to ascertain the family's life style and the effects of their surroundings (local community) and general living conditions (larger society). The social and psychological patterns that were laid down before the disabled child was born; or before the disability was noted are important because this influences the way the family will cope with the incident. In this case the situation of the families before acquiring a disabled child was found to be average or poor based on the families own experience of the situation.

Young or first time mothers stated that life was good in the sense that they were still teenagers at home, had no responsibilities and could come and go as they pleased. From this situation they then got married and were now being looked after by their husbands. As a result when asked to state what life was like before the disabled child was born, their response was that life was 'good'. On the other hand, older mothers and grandmothers stated that life was good in the sense that there were no disturbances in their everyday life situation e.g. they could go to fetch water and leaving the children behind without fear that one may fall into the fire etc.

Both give a standard of 'normality' although one sees a life of marginal resources as noted by the way women were always busy trying to get food for the family; climbing up trees, food for work, walking long distances to relatives to beg for food etc activities. The constraints are there for us to see but there was nothing major disturbing them from pursuing their everyday activities.

#### 4.8 - Disability as life event or crisis?

When having a child, the Tonga like the Tswana (Ingstad, 1997) were mainly worried about whether or not the child will survive; and not the presence of a visible disability. Bodily imperfections were seen as important only to the extent that they impaired normal functioning in society, and life was seen as superior to death. Disability was a secondary matter as noticed in the proverb; *'kocilema kunywigwa maanzi'*. The mothers would rather have a disabled child than a dead one. The mothers' reactions (below) could be the reactions of any person when a crisis takes place, and the researcher would like to emphasise that the Tonga loved their disabled children.

When asked to state their reactions on discovering their child's disability the researcher noted the different reactions of the young mothers from that of the middle aged, older mothers and grandmothers. To the young mothers, it was a *'crisis'* whereas to the rest, it was a *'life event'*. The young mothers, although they had grown up with life's difficulties like poverty, they had not experienced *'real'* hard times like the rest of their women folk who saw the birth of a disabled child as *'one of those things that happen in life'*.

*My neighbour noticed that the child was disabled at four months and told my husband and I the news. The child could not sit up unaided, had poor head control and a bent neck. She drooled all the time and had a cold body. I cried a lot for a long time. Moyo wako zvoloko \ zakatichisa' meaning that the news was painful. I blamed my co-wife for the child's disability because we had exchanged words a few months before I gave birth. My husband said that he had already noticed the disability and concluded that the child was bewitched'.*

Another young mother stated that her reaction to the news was; *'But it is my first born child. I was not expecting that to happen. I had feelings of anger against God. I did not talk to anyone for a long time'*.

To some young mothers, the birth of a disabled child was *'a great tragedy'*. They experienced reactions more in line with patterns described by Cullberg (1966, 1979) and Caplan (1981), starting with an initial period of shock followed by a period of strong emotional reactions and eventually a phase of reorganising their lives. The reactions of the young as well as first time mothers were noted to be in line with resentment. The situation

resulted in; crying a lot---depression---not talking to anyone and asking the question ‘*Why me?*’

One grandmother’s reaction to the findings were; *‘I thought that my grandson was a ‘late starter’ but later decided that the child was disabled at the age of six months when he started taking the ‘W’ sitting position, (i.e. sitting on his knees) and falling to his left side. I knew then that he had been bewitched. I just thought to myself that it is one of those things that happen in life. I then told my husband who said that we would get through the problem. I felt sad for the baby’.*

Another mother stated; *‘I was happy but sad for the baby’.* This was one of the mothers that told the researcher of the Tonga proverb. To her she was better off having the disabled child than a dead one.

When the researcher enquired how the siblings reacted towards the news, the mothers just shrugged their shoulders and said, *‘they did not mind when they were told the news’.* The relatives reaction was; *‘not to worry, these things do happen. We are neither the first nor the last family to have a disabled child’.*

In analysing family coping among the Tonga, I found that the meaning that parents attached to the experience of getting a disabled child varied. This variation seemed to be related to their own (sub) cultural background, their previous life experiences and their initial expectations for the child. When asked to describe their reactions to the first information about the child’s disability, nearly all the young and first time mothers pronounced it as *‘a great tragedy’* whereas the rest of the parents said *‘it was one of those things that happen in life’.*

In this case the young mothers saw the situation as a tragedy maybe because like any mother, one expects a ‘normal’ child; and being young, such a situation may seem the end of the world especially when it comes to coping with the disabled child. Their socio-economic situation does not help either and there is also the fact of lack of previous experience of mothering. In the case of the older mothers and grandmothers their coping behaviour and attitudes are seen to be shaped by interplay between socio-cultural factors and previous

experiences. In their case, the news of disability is met quietly and with dignity, but also with ample room for feelings of sorrow and worry.

Discourses on emotional experiences of having a disabled child (Tswana) re' 'feeling sorry' related to their cultural notions of self and personhood, life and death, their previous experiences of having children, their maternal environment and struggle for viability as well as their emphasis on collective responsibility (Ingstad, 1997). In this study, the Tonga parents elaborated their 'sorrow' in the sense that their children were not going to be mobile so as to become useful members of society. In a way, they were talking about their life situation and struggle for survival.

#### **4.9 - Life after child with disability was born**

Previous life experiences in coping with critical life events are a major importance for how parents come to cope with a disabled child. Ingstad and Sommerschild, (1983, 1984) found that patterns of coping with problems, sometimes of different kinds, were handed down as culturally and circumstantially constructed models for better or worse. They continue to state how individuals come to deal with such models, as examples to be copied or rejected, depends on a number of outside factors but also on what we may call individual character and individual resilience.

The researcher found this among the Tonga women. When asked how they coped with their families, most stated that they were used to a life of suffering. They had seen their parents and grandparents go through hard times so this was not new to them. On reading literature about the Tonga, I found that people who have come across the Tonga state the fact that they are one of the poorest communities in the country, if not the poorest. Tonga life seems to be synonymously known with suffering.

All the families stated that their biggest problem was to find money in order to get treatment for the disabled child. This was treatment for the 'disability' as well as opportunistic infections like pneumonia, chest infections and diarrhoea to mention a few. A few could afford to take the children to the hospital whenever they could afford it and not when they had to. The researcher remembers getting to a homestead where a child was gravely ill and had to take the mother and child back to Bonga hospital in the evening on our way back.

One young mother reported; *'Now life is different. The child frets a lot and needs to be with me all the time. I find it difficult to leave her behind because she has no head control, drools and cries most of the time. This upsets me when I have to go and fetch water or firewood. I sometimes have to go and work at the irrigation for other families so as to get food for work (e.g. beans or other grains). I have to have the baby on my back unlike other women who can put down their babies in the fields. I trust my grandmother and sister in law to look after the child when I have to leave it behind. I have problems visiting relatives because the child is sick most of the time so I stay at home. I now need to earn some money for hospital fees or the traditional healer medicine. Sometimes my grandmother helps by providing home remedies for diarrhoea and fever'*.

The above mother stated that life had become stressful with the above situation as well as the numerous traditional healer and hospital visits. In this case the child's disability and the fact that she has to put her on her back most of the time makes coping difficult. The mother reported going to work less times and so earning less as before. This meant that the family was getting poorer as a result of having a disabled child in the family.

One grandmother seemed to look after their grandson without complaining much. On being asked to describe what life was like after the disabled child was born, she stated; *'We have no problems as such, only when he is not well that the family have to make sure that he is looked after well. Life before the child was born and today is all the same to this family. Nothing has really changed. The extended family all help whenever help is needed – I can still leave the child with the family and get on with my work and the other children help too – I have not many problems'*.

A few families stated that they were poorer as a result of having a child with disabilities. One mother stated, *'After the birth of the child, life changed in the sense that I had to be home all the time looking after him. He is a sickly child and needs attention at Binga hospital most of the time. This disturbs the family from getting the earnings that we used to get resulting in economic hardships for us all'* This is a family that relied on basket weaving and buying and selling dried fish to other communities.

Generally, a life living with a disabled child comes across as difficult due to the needs of the child, e.g. money for treatments. With the young mothers, inexperience also plays a part in that they may not know how best to deal with some of their problems compared to experienced mothers. In this case, an experienced mother \ grandmother may know the traditional herbs for diarrhoea, fever etc whereby when this is needed, they just go and get the medicine and treat the child or get it from friends. This may be not so easy for the young mother until she can trust the people around her otherwise she has to try and get money to take the child to the hospital or clinic.

The case of Peter shows his mother having to look after her family of six children as well as Peter's disabled aunt and her little daughter. This from an outsider's point of view is a remarkable task which demands great resilience. Personality factors are one of those variables on the model of coping with disability. There is still the question of how emotional expressions are culturally constructed and mediated as cultural patterns. Individual resilience and reactions to stressors is still not much understood. As a result what we know is that some people can cope with situations whilst some cannot cope with the same situation. In her case she had seen her mother coping with her disabled sister and took over from her mother when she died. Having Peter was therefore not a shock but an incident that the family could manage despite lack of resources. In her case it is experience as well as resilience.

The Tonga socio-economic status seems to be their biggest downfall. It was interesting to see how the Tonga were very much concerned about letting an outsider know about their history. Before the study I had scanty information about the Tonga, only to be filled in by the villagers themselves wherever I went. This was a community that was so keen on letting people know about their past. Later I understood that one needed all that in order to understand how they survived their predicament. Poverty and suffering was not a new phenomenon to them.

#### **4.10 - Stigma, guilt and shame**

As human beings, we all tend to search for a meaning when an incident takes place in our lives, especially one that disturbs the balance in our lives. We seek an answer to the question, '*why did it happen to us and why now?*' The researcher found that the Tonga parents had the

same above question just as Ingstad (1988) found in her study of the Norwegian as well as the Tswana parents. The search for a meaning was common to all the three cultures.

The answer to that in a Western society is likely to bring an answer that puts the blame on oneself, creating feelings of guilt on the mother or the father of the child. There is also the concept of 'God's will' found among all the three cultures but having different meanings. The Batswana and the Tonga meaning of the above is seen as a positive sign of trust in the parent's ability to care for a special child. Among the Tswana, the name Mpho ya Modimo, a gift from God; as well as Kabelo, meaning present or gift. The Tonga had names like Twalumba, meaning thank you and Chipo meaning gift. On the other hand the Norwegian families expressed a feeling of being punished by God for their wrong doings.

The Tswana as well as the Tonga cultural construction of meaning seems to be part of the explanation why feelings of guilt were hardly expressed by the parents. The researcher discussed the issue at length with the mothers during focus group discussions and it was noted that they did not have feelings of guilt at all. What I found instead was that the parents had guilt feelings related to not being able to do enough for the disabled child; a phenomenon which was common to the other two studies.

As noted before, the Tonga were concerned with the reason or origin of the disability and this was for the purposes of attempting to find a cure. In the study, all the families did not blame witchcraft on the victims but rather the people who had done it e.g. co-wives or neighbours. This in a way relieves the potential burden of guilt on the parents. On the other hand Ingstad found that Norwegian parents' feelings of guilt were closely related to the feelings of shame with stigmatisation as its social consequence. Their fear of stigmatisation was related to receiving social benefits for their child.

#### **4.11 - Family needs**

All the participants stated that all they needed was basic food. As stated before (background chapter) most families were having one meal a day or nothing till the next day or so. This was their priority need followed by clothes. Some of them stated; '*The Tonga don't mind many things – just food and clothes*'. In this case, malnutrition is seen as one of the fundamental problems of health among the Tonga. It is a cause of disease, contributes to many diseases



and the cause of death especially among the children. The researcher and assistant attended one baby funeral and I found this to be one of the saddest funerals I had ever attended in my life. It was the other babies with their mothers that I was sad for and not the dead one. It was because they did not look healthy. My fears were confirmed when just after I had left the area, I had news of deaths of a few others including two from the study.

One young mother stated; *'I need to get food to improve the child's status so that he is able to sit and walk like other children'*. Mobilisation seemed to be one of the major expectations of the parents for their disabled children (discussed before). This was very important to the whole family. Families need to be able to get on with their work at home and the fields so, a walking child is of great help because he \ she will be able to assist the family; and in some cases care for the parents in their old age.

The mothers were lamenting the 'Binga porridge' as well as the Government \ NGO porridge that they used to get and feed their under five years old children. This was a free porridge supplied by the government through the hospital. The porridge would be delivered to central points where the mothers would take it in turns to cook and give it to the children. The porridge had nutrients added to the meal such that the mothers just add water, cook it and give it to the children. Unfortunately, this arrangement had stopped before the researcher started the study. The deliveries could not be made due to the unavailability of fuel.

This put the mothers into a very difficult position because they could not afford the maize meal needed to make the porridge together with the sugar, salt and milk. Only a few could afford it (maize meal and salt), the rest could not even afford the maize meal. If the maize meal was available, they made porridge with 'busika' (a dried wild sour fruit) added to it so as to give it a sour taste and palatable. In some parts of the district, the mothers also added moringa (zakalanda) leaves (dried and crushed to pulp) as medicine for the sick children. Moringa, dubbed the 'miracle tree' is believed by the Tonga to cure many illnesses and is available only in the Binga area. Its use is recommended by both medical doctors and traditional healers.

Parents needed clothes for the children. The researcher also noted that this was a problem because most children were scantily dressed. The girls mostly had either a dress or a skirt and

a blouse that was torn and tied with some form of a belt. The boys had either a shirt or a short; rarely having both.

Two children (boys) with disabilities did not have any clothes on when we arrived at the homesteads. One was two and the other one three years of age. One grandmother explained that the child had only one pair of clothes and so this was used when they had to attend the hospital or other functions with the child. The other grandmother explained that the child did not have clothes of his own but borrows from one of his uncles when they needed to take the child to the hospital or village meetings. This was one situation that nearly led me to accuse the grandmothers of neglect. I had to have a heart to heart talk with my assistant who asked the question; ‘What do you want the old lady to do?’ I looked at the family situation and decided that there were many problems in the family and so I really did not have a right to judge the situation.

There was also the need for money. For many parents, this was to help with purchasing of household wares and when seeking treatment for the child. A few mentioned school fees for the children. This is because many children do not attend school due to lack of funds and other problems (to be discussed later).

Three parents who lived in a village that had had Community Based Rehabilitation activities (1990s) had some understanding of the role of government towards disabled children. After food and clothes, they stated their other need as places at a special school (boarding facility) for their children in Bulawayo because this is their nearest city. Two children had behavioural problems and the other one was multi – handicapped. They stated, *‘The government should allow our children to attend special schools depending on their conditions – the child should be put in a home because he is better off where he can get food and be taken care of well’*. The two schools were St Francis for the multiply handicapped as well as King George for the physically disabled. One parent had the need of a wheelchair for their ‘athetoid’ cerebral palsy child.

The parents also expressed the need for domestic animals for cultivating as well as for food; for example cows, goats, pigs, donkeys and sheep (depending on the area). They stated that they used to have some, i.e. big or small herds but due to the drought and poverty, most of them died or were sold for food, clothes or school fees. Some stated; *‘We cultivate by hand*

*for we do not have a plough as well as the cows. This results in reaping small amounts of grain from the fields' Some said; 'We do not get much out of the fields because when the rains start, we help families who have ploughs first and then we get to use their plough on our lands. In most cases, this makes us fall behind and results in a poor harvest'. Most women lamented the days when they had chickens to eat as well as exchange for money, clothes or food. Most villages did not have chickens because of the 'Newcastle disease' that had wiped out chickens in the district just before the study period.*

Looking at coping and the needs of the Tonga, one has to think of how one can manage everyday life with such a huge lack of resources. Coping, according to the model used in this study has to do with the mastering of both the emotional and the practical sides of life when a critical incident occurs (Ingstad, 1988). As it is, this paper has already noted the changes that have occurred in the lives of the participants' life situation due to having a disabled child; e.g. having to work less time in their fields due to hospital or traditional healer visits resulting in a poorer economic situation for the family; adding a threat to the survival of the child with disabilities. In Peter's case lack of hospital fees led to his death.

#### **4.12 - The Traditional healer**

All the 30 families interviewed stated that they had visited the traditional healer when they discovered that the child was disabled (and afterwards). This was the first port of call. When asked whether they noticed any improvements, most of them stated that there was no improvement. One family said they noted a little improvement after the child had a frenulum cut by the traditional healer because after this he was able to produce some sounds but was still unable to speak. To them, it was a little improvement (some families did not find any changes after the same type of operation). Some reported that the child did show some improvements, e.g. the child started crawling etc.

*'We took the child to the traditional healer and were told that he had a broken back, and that was why he could not sit independently. After all the treatments, nothing has changed and now we have stopped going'. This was from one of the parents of an athetoid cerebral palsy child.*

*'After all the treatments, nothing has changed and so we have now decided to take care of him and not bother about treatments – we did try, but it did not work'*. These were some of the families that had decided not to take up any more treatments for the child. During focus group discussions it was interesting to note that some of the mothers stated that if they hear of someone who can cure their child, they were prepared to try again. During participant observation, the researcher heard some grandmothers saying that if they had money, they would take it upon themselves to make sure that they visited a n'anga far away who may have a cure for the grandchild.

The above statements show the participants' love of their children and how lack of resources is their main barrier in getting help for the children. For many, this was the end of their search for treatment. As noted by the researcher, many of the children could have been helped by rehabilitation but because this was not within their reach, the children had to suffer for the rest of their lives, if at all they were lucky to have a life.

#### **4.13 - The Doctor – Rehabilitation Technician**

*'We have heard of a child who is now able to walk with the help of rehabilitation technicians. When the family can afford it, we will take the child to the rehabilitation department'*. This was echoed by a few families who lived in a village not far from the district hospital. They had had community based rehabilitation activities in the early 1990's. The chief also had some knowledge and did encourage families to attend the hospital if they can afford it. We gathered this information from the chief as well as the participants themselves. Both the chief and the participants cited economic hardships. The researcher, being an occupational therapist, found this unacceptable since many of these children and families could be helped by rehabilitation through assessments, treatments, the provision of equipment and psychosocial support.

About 20 families out of 30 had not visited the district hospital where there was a rehabilitation department. The 10 families that had done so, were the ones that had either given birth at the hospital or had taken the child to out patients for health reasons and then been referred to the department.

Only one mother had a 'corner' seat (seat which helps child to sit up) that she was using at home. Another one had a cardboard box that she sat the child in when she was carrying out household chores. This was at the fishing camps where the mother would be busy drying out the fish in the sun for sale to the villagers and other business people from outside the district. Parallel walking bars had been recommended for some of the children but maybe the parents did not understand the importance. During the visits, some referred participants managed to bring their children to the hospital and the researcher and assistant managed to measure the children and corner seats were issued to the parents. The mothers were also shown how to carry out physical exercises on the children as well as stimulation activities.

Written literature was not given in most cases because the mothers could not read. After this first visit, most did not attend again due to lack of funds to travel to the hospital as well as pay for the treatments. There was no follow up due to staff and fuel shortages. By the time the researcher finished her study, the department had run out of corner seat material and the rehabilitation technicians stated that they did not know when they will get the next delivery from the Ministry.

#### **4.14 - The spiritual healer (churches)**

Christianity is not so widely accepted a religion in this area and is only represented by a small number of congregations among the Tonga. Many of the old ways and beliefs still live on and have not taken on a Christian appearance. The Tonga still believe in one of their greatest 'river' Gods, the well known 'Nyaminyami', their provider and protector. Before the evictions they would brew beer and go to the river and carry out the ritual to appease the god. This 'snake like' water animal was reported to be seen occasionally when the Tonga lived in the valley and it disappeared after the dam was built. All they have now is the folk stories of the 'Nyaminyami' to the young generation. However, each family is believed to be under the supervision of its own ancestors on the female side who would punish or protect their living relatives according to their upholding of traditional norms and values.

*'I attend the Church of Christ but this does not help at all – I attend the Zion church and my mother in law detests this for she attends the Catholic Church. She does not like the Zionists praying for the child because she says it does not help and gives us false hopes'.* Some stated that they used to attend but do not do so anymore because they could not see any changes in

the child. One wonders whether this was the only reason why they attended church. As stated before, this was mainly the young mothers.

According to the participants, the positive side of attending spiritual churches is the spiritual support that they get from the prophets and the congregation. The church also prophecies to be able to pray for '*bad spirits*' or '*demons*' to leave the child. Maybe this in a way makes the child '*pure*' and '*blameless*' such that they can now look after it. They also get encouraging words to keep taking good care of the child for he \ she is a gift from God.

The move to the '*new*' spiritual churches according to Luig, (1999) is that people are losing faith in their spirit mediums (*basangu*) which centuries ago were their influential leaders. The move is a result of outside influence that took place during and after the resettlement when the people of the valley got more involved with the Zambian state, European influences, the education system and the Christian churches made their impact felt. In some cases, ministers and their supporters attacked local beliefs in spirits as well as in witches as superstition. They would at times burn people's '*fetishes*' in order to demonstrate their own power.

Luig states that the decline in spirit medium beliefs could be due to processes of secularisation as a result of the fundamental changes people of the valley underwent in this century. She states that the most important argument against the assumption of disenchantment (disillusion) is the increase in numbers of Christian churches and the continued success of masabe spirit possession, which attract people in great numbers. 'It seems that it is not a problem of secularisation but a question of how meaningful the interpretations of specific cults still are for local people to come to terms with their increasingly complex worlds in times of social change' (Luig, 1999).

Masabe spirit possession attracts people in great numbers because of their approach of '*global modernity*'. It is an organized cult of affliction which addresses itself to the individual instead of the community; afflicts a person with illness in order to make their wishes known and disclose their identity either in dreams or through divination by a masabe healer. They are judged informally by their success in healing as their therapy is oriented towards the socialisation of spirits into the world of humans and the gradual familiarisation of humans with the spirit world.

As noted before, most of the congregation of these 'spiritual churches' are people who are afflicted with all sorts of problems e.g. in this study it is mothers with disabled children. The combination of spirit possession (which is part of their culture) and Christianity (modernity) enables the people to embrace the new churches with the notion that they are still following their culture which has been modernised unlike the old churches like the Roman Catholic which discourages acts like spirit possession.

A few stated, '*Maybe one day he \ she will be able to walk and talk*'. The researcher could detect some hope or maybe desperation in some of the mothers. Still, this is what they have chosen to do, and so the men leave them to it. The researcher sees this as a form of psychosocial support outside the home.

#### **4.15 - Role of Health Services**

As stated before, Binga is one of Zimbabwe's most underdeveloped district, maybe the worst (see background chapter). The researcher had the privilege of camping and sleeping at five of the clinics during rounds of in depth interviews. The clinics for a start are not well manned by trained staff. The district hospital, one mission hospital, one mission clinic and two other clinics had fully qualified staff. The other clinics had nurse aides who had had six months experience working with qualified staff. These aides were in charge of the clinics. One clinic was shut down due to water shortages. Most clinics in the district were empty. This was not because of a lack of treatable pathology; rather patients had no money to pay for such care and most of the time some medicines were not available.

The nurse aides stated that they were there to help the community as much as they could, and if not, the patients were supposed to attend the district hospital for major health problems. Birth complications used to be sent to the district hospital, but due to fuel shortages, women were losing their lives as well as their babies. Most clinics were run down except for the one mission hospital and clinic. Of the nine clinics, one had electricity as well as the district hospital. The rest either had a generator (not working due to fuel shortages) or nothing at all. The clinics were also very far from each other. The villagers had to walk long distances like 14 kilometres from one clinic to the next in some cases.

‘Safe motherhood is a Human Right---if the system lets a woman die, then the system has failed. Our task and the task of many like us---is to ensure that ---safe motherhood is not regarded as a fringe issue, but as a central issue’ (Wolfensohn 1998 – President of the World Bank).

During chats with the different nursing staff, I gathered that most pregnant women could not afford to attend clinics as they used to before due to economical constraints. The transport fares kept going up and were now beyond the reach of the community. This has resulted in a high number of home births by traditional birth attendants (TBA), together with the complications that go with it like the death of the mother or infant or both. One could see the number of children born with disabilities increasing in the community due to this unfortunate situation.

The same situation was taking place at the district hospital. The Zimbabwe Herald (national newspaper) 14-12-05 read; **‘Hospital goes without doctor for six months’** – Binga rural hospital has been without a doctor for more than six months, forcing thousands of patients to travel as far as Bulawayo – about 450 kilometres away. In an interview yesterday, Binga district administrator Mr Cephas Mutale said the situation was further compounded by a critical shortage of qualified nurses at clinics throughout the remote district.---*‘Our clinics are being manned by unqualified nurses, mainly school leavers, who are elevated to nurse aides after some time’* said Mr Mutale. *‘The situation is particularly difficult for women as they often develop complications during pregnancy’*. The Minister of Health’s response was; *‘We are fighting to have at least two doctors in this district---It pains us as a government to have such a situation, but we are trying our best to address the situation’*.

The above situation led to a number of deaths, disabilities, orphans, widowers and widows. The nearby Catholic priests tried to help at times with fuel but in most cases it was too late for patients died on the way to the nearest hospital. On Wednesday 26<sup>th</sup> October 2005, at Binga hospital, the two ambulances had no diesel and efforts to get some were futile. Two pregnant mothers developed complications during labour but could not be transferred to the nearest hospital of St Luke’s outside the district. Later the Catholic fathers managed to get some but unfortunately one mother gave birth to a dead baby during the journey; and the other mother had a caesarean section at the hospital but the baby was already dead. In some cases, mothers and babies died during transportation or in the hospital.



Chipanda ward (Binga hospital) is a building outside the hospital where pregnant mothers due to deliver are housed. They come on their own or with family to help with their cooking as well as walking or getting on the bus to get back home with the new baby. During the study, the women had to be advised to go back home and get more money and get to a hospital where there was a doctor. It was sad to note that only a few did that. The rest stayed because they said that they could not manage to get any more money and so took the risk. They just hoped that they do not present with complications that will either kill them or the baby.

. There is also an urgent need to address the problem of maternal mortality. ‘Contrary to the Safe Motherhood Initiative, maternal deaths in developing countries, especially Africa, may actually be increasing’ (Yamin 2005) this is true in the case of Zimbabwe. This is social suffering and structural violence on a defenceless people.

#### **4.16 - Role of Community Based Rehabilitation: (CBR)**

Community based rehabilitation in Binga was launched in 1989 in three wards. In 1994 it was expanded to three more wards. As a result, only six wards out of twenty – one had CBR activities. This was stopped due to lack of funding when the Swedish International Development Aid (SIDA) moved out in 1996 and the government had not put anything sustainable in place to keep the activities going. Therefore, at present, there are no activities taking place. There is one rehabilitation department at the district hospital for the whole population. More departments are needed but as stated before, the economic decline as well as the ‘brain drain’ has affected health service delivery in Zimbabwe.

The six wards that had rehabilitation activities are all near each other and near the district hospital where the rehabilitation department is situated. This has resulted in people with disabilities not benefiting much from the rehabilitation services due to long distances to the nearest rehabilitation centre. During chats with the district therapist and rehabilitation technicians, they all echoed the need for outreach services, i.e. awareness campaigns for a start and then different activities like ‘neuro developmental clinics’ especially for mothers of children with cerebral palsy and other developmental problems. Lack of government funds was cited as the major problem for such activities to be implemented.

The principles of Community Based Rehabilitation were not being implemented. There were no programmes aiming at reaching disabled people in their local communities; no working along with them; utilisation of local resources; and keeping programmes at a 'low cost' level so as to reach as many as possible. There were no institution-based, out-reach or community based activities present.

The researcher visited the 'Tomba' project that had managed to survive since the nineties. This is a wood carving project run by three male amputees. Their major problem was getting new tools to use as well as the tourists to buy their products. We also visited a women's defunct sewing project. The women were no longer sewing and selling because the machines were broken down and they could not afford to get them repaired. There was also the high cost of materials.

This unfortunate situation was noticed during data collection whereby participants who had had a little knowledge of CBR seemed to be more aware of how to help themselves. A lot came out in the focus group discussions when mothers were asked how they could help themselves take care of their children with disabilities. The parents from non – CBR wards seemed not to have ideas on simple income generating projects compared to the others. Some learnt of the benefits of rehabilitation during the discussions as well as the talk from the research assistant who is a rehabilitation technician at the hospital. The participants who had attended the department regularly found it helpful as stated;

*'Rehabilitation was very helpful. The rehabilitation technician gave us advice on how we were to look after or train our children depending on the condition - Rehabilitation stretched the child's hand and now he is able to use the hand - It has also helped the child to walk a little bit - My child is now able to feed but the problem is the food shortage at home'.*

One mother stated that after the baby was born, the rehabilitation technician had explained that the baby was likely to be disabled. This was a hospital birth with complications. The child was now three years old, and the parents were thinking that if they get some money, they will take the child back to the hospital because after all, they know what they are talking about. The technicians maybe able to help the child to sit, crawl and walk. The mother who had 'a corner seat' stated that it had helped her child to sit up unaided. One grandmother

stated that she too was going to take the child to the department for she had heard of a child who is now able to walk with the help of rehabilitation technicians (this was going to take place after securing some funds).

Most mothers wanted their children to be able to walk so that *'they have less problems'*. A few mothers that had attended the rehabilitation department thought that it was not helping and so they stopped going. Looking through the department records, these mothers had not attended as regularly as they should have because of lack of funds. All in all those that had attended regularly portrayed a good picture of the department on its usefulness in helping their children; which in turn helped with their coping with a child with disabilities in the home. Understanding the nature of the disability helps with coping. There was a great lack of it among the parents.

#### **4.17 - The Role of Education**

The Convention on the Rights of the Child mandates that States make primary education compulsory and available free, to all children. It also requires that children with disabilities have access to and receive education in a manner which will help each child to achieve the fullest possible social integration and individual development. However, the current situation for children with disabilities from developing countries is not encouraging (Price, P. 2003). The Zimbabwean government once had *'free primary school'* education for all just after independence in 1980 up till the early 1990's when the economy started to decline. Since then, parents have had to pay their children's school fees.

Education is a basic human right and all children, including children with disabilities, have a right to education. This right has been upheld in the Universal Declaration of Human Rights (1948) up to the Millennium Development goals (2000). Lack of access to education, remains the key risk factor for poverty and exclusion of all children, both, those with disabilities and those without.

Most children who attend school in Zimbabwe are the few that have parents who are still able to pay the school fees. The other is a small group of AIDS orphans and other vulnerable children (OVC) who get their fees paid for by the government. Education is now out of reach for most children in Zimbabwe both in urban and rural areas. As stated before, the situation

for children with disabilities gets worse because most of their parents are poor. In Binga, schools are few and far apart. This can be 10 or so kilometres. At the homesteads the researcher was told (by the children) *'The school is too far, we reach the school tired. There is no porridge or drinking water at the school. No bridges on the rivers for us to cross safely during the rainy season'*. One can ask the question; 'Where does this leave the child with disabilities with mobility and other problems'?

For most part of the year the temperatures can get to 42 C; parents have no food for the children to take to school; some children have to start as early as 0430hrs and get back home around 1800hrs; and in some areas, children can be attacked by elephants and other wild animals on their way to and from school.

In their study of (2002); Save the Children (U.K.) found that 84% of teachers in the primary schools in Binga were untrained; at one school all the teachers were untrained except the headmaster. This further disadvantages the disabled child because an untrained teacher would not know how to handle as well as teach the child. This means that there is an urgent need to facilitate the recruitment of trained teachers as well as in service training programmes for temporary teachers. The majority of schools had no electricity which is likely to impact negatively on the provision of quality education as the lack of electricity may limit the scope of activities that can be carried out at the schools. Most schools were generally in a state of disrepair, had no school gardens and library facilities.

The results of the study also showed that the age of starting school ranged from 5 years to 16 years with the majority of children starting grade one between 6 and 9 years. Reasons for starting school late were; financial problems and rejoin later; parents or grandparents not able to organise schooling for the children on time and some children especially orphans stayed for some years not going to school following the death of parents. (About 50% of children with disabilities were not attending school – this was information from the local rehabilitation centre).

At the moment it is only Save the Children (U.K.) that is actively involved in the education of orphans and other vulnerable children in Binga. There are some small organisations (NGO's) like CAMFED (Campaigning for Female Education) that pay fees, levies, stationery and school uniforms. The rest of the children have their fees paid for by their parents. Fewer girls

than boys attend school. The researcher had an opportunity to discuss (on several occasions) the educational situation for children with disabilities. The educational officer stated that it was unfortunate because there was no reliable register of children with disabilities which they could rely on. Due to the long distances for parents to get to the Save offices, this made it difficult for the officers to help. There was need for the community to identify these children in order for them to be assisted to attend school.

There were a few day-care centres and these were mainly for teachers, nurses and other professional people because they had to pay fees. For a disabled child from a poor family, a place in a day-care centre was out of the question unless donations could be found. This means that mothers of disabled children had to take care of their children for twenty four hours of the day whilst the other mothers were having respite during the day when their own children were at school. This should really be the other way round. Coping becomes difficult in such circumstances. The government should come up with some measures to help the 'disabled families'. To expect that these parents give priorities to the interests of disabled children before the able-bodied ones may be too much to ask.

The numerous problems faced by the Tonga have made them one of the least areas to have educated children unlike the rest of Zimbabwe. Children have no role models and their parents still do not appreciate the importance of education due to lack of education on their part. This is not a new thing since the situation has been like that from the previous government up to date. Their socio-economic and political situation is a great barrier.

Lack of educational opportunities manifested itself mainly in women. It was sad to see the gross lack of knowledge the women had. In the study, two had eleven years of education but failed all the subjects. The rest of the mothers had either no education at all or few had three to four years of education. At one homestead during participant observation, one mother had three year old twins, of different sexes. The little boy was crying and crawling due to painful knees. My assistant gave the mother some paracetamol tablets to give to the boy. Just as the mother was getting the boy to swallow the tablet, the little girl cried for one. To our horror, the mother popped the tablet into the girl's mouth and gave her water to drink before we could do anything. When asked why she did that, she stated that it was because the little girl wanted it as well. I suppose it is a case of '*if the tablet can make my son better, surely it cannot be harmful to my daughter*'. That evening we had to explain the proper use of medicines.

The implication of lack of education is a tragedy especially for women in a community, let alone a matrilineal society. Women are the ones that take care of the family, and it is of utmost importance for them to be educationally empowered so that they are able to make informed decisions, thereby helping themselves as well as the family. This is one of the constraints under which care is given and makes coping very difficult.

It is an undisputable saying that if you educate a woman you educate a nation. Tonga women have got numerous problems due to lack of education. The government has got a duty to see to it that every child should be given a chance to have some education so that as adults, they can manage to help themselves.

Despite the numerous constraints faced by the families, the researcher did not come across any patterns of preferential treatment or neglect of the disabled children. Like Scheper-Hughes (1998), I asked the women to share with me their thoughts and feelings about motherhood, family life, joy and affliction about loss and grief. Neither the reproductive histories nor the interviews revealed a strong sex or birth order bias. I half expected that they would have a bias towards the male child than the female but this was not the case. Maybe it is the case that this is a matrilineal society unlike the rest of Zimbabwe. Still, in some families (patrilineal) that I know of, the culture of male preference in children is slowly dying out due to a changing culture. When asked why their children were malnourished and sick, they stated that it was because they were poor and did not have enough food to eat.

#### **4.18 - Coping with care**

As stated before in the literature review, the researcher used a 'Model of coping with disability' (Ingstad and Sommerschild; 1983). The model includes culture as an important variable since without it; theories of coping behaviour have resulted in more or less universal patterns of reactions with no reservations made about possible cultural diversities Caplan, (1981); and Cullberg, (1966; 1979). Therefore culture as well as other social factors like political etc were some of the variables used in order to find out how families were coping with care of their disabled children.

In coping with care of disabled children, (Ingstad and Sommerschild 1984) introduced the concept of a 'disabled family' meaning that in a family with a disabled member; the whole household may be affected. In this case the concept is useful as an analytical tool in that it opens up for an understanding of the processes of care.

An analysis of coping according to this model is not only a question of giving a description of the observable social forms (e.g. patterns of family interaction) but of understanding and explaining the social processes that generate them. A lot of the information in this study was collected through in-depth interviews and some through participant observation. Family life situations were looked at from the time before the family acquired the disabled child or before the disability was noted. The researcher at this point was looking at variables like; family ethno medical beliefs, childhood experiences, personality factors, attitudes as well as socio-economic variables because they play a part in coping with a disabled child.

The situation of the family before they acquired a disabled child was roughly classified as *good, average and poor*. The researcher based this on the family's own experiences of the situation. The families had to again come up with their situation after the incident occurred. This was termed; *better, worse or unchanged*. Looking at the three cases, Annie's case started as an average case whereby her father and mother were helping each other to cope with their household. After Annie's disability was noted, the father left and the mother was now having to cope all on her own with more or less nothing much coming into the household as before. This makes the family fall into the worse category. Joe's case started as an average case with the grandparents just about managing, selling their livestock (when needed) to purchase maize meal etc, had meat and milk from the goats and chickens, and support from the extended family. Their situation changed from average to unchanged. Peter's case started as poor with his mother working mostly single handed to feed the family as well as the extended family and looking after his disabled aunt and her daughter. Their situation changed from poor to worse for she now had to manage Peter as well as his epilepsy.

The researcher found that this was the common pattern that was noticed with the participants. There was no family that had started as good and ended up better. The participants also reported that the process of coping usually had an uneven course, sometimes going up and sometimes down. An example given was that it would go up during the harvest season when they had food from the fields as well as water in the nearby rivers. At this time of the year

they had resources to meet their material needs. The researcher also noted that in families where the extended families helped with care of the child, the mother was not so much stressed and reported that she was managing. Some of the mothers reported that coping was difficult because they had to have the child on their backs most of the time. This was because the child was too sick or disabled (athetoid cerebral palsy) to be left with the other children whilst the mother carried on with household chores.

By emphasising the family's own experience of the situation as important in evaluating their coping, socio- cultural variables are strongly brought into the picture. In this case the child is seen as having been bewitched, people's attitude towards the disabled child, the parents childhood experiences as well as personality factors have been noted to be of benefit to their coping with the disabled child. The researcher also noted that when making their own judgement, family members compared their life situation to what they feel it would have been without a disabled child; hence the remarks from one grandmother, *'Life has changed for the baby needs my attention most of the time. I have to carry her on my back and this is going to be a problem come the rainy season whereby I have to walk to the fields four kilometres each day. I am getting old and do not have the strength to continue doing so. Still, God will help us'*.

This grandmother felt that the baby was going to slow her down during the rainy season and that probably she would not have much strength left after walking (baby on her back) to work in the fields. This would then result in a poor harvest, a situation that started when she got the disabled child. In a way she is telling us that life would have been different. It was noted that the participants also compared their new situation with the life of other people living around them and with whom they identify.

In conclusion, (Ingstad, 1988) *suggests that 'cultural influences shape the process of coping through emotional patterning, expectations of life and future, life experiences and actual opportunities. Culture also provides a frame of reference for critical life events and gives a particular content of meaning to them'*. This makes culture an important variable along with others to be taken into consideration in studies of coping with care for a disabled person.



## CHAPTER 5 DISCUSSION

A look through the lens of history shows the way a people – a social group, a subculture, a community, or a whole country – is laid open by the course of important economic, political, and ideological changes to new perception, new patternings of behaviour and belief, new ways of seeing what is happening to them (Mintz 1960:253). ‘*Laid open*’ in this case refers to the poor Tonga villages. As one enters the villages, one captures both the violence and the vulnerability that characterise the life of the Tonga. They are pawns in an economic and political scheme that has left them laid open. As stated before, they are a defeated people.

Farmer and Kleinman, (1998) stated; ‘*Suffering is a culturally and personally distinctive form of affliction of the human spirit. If pain is distress of the body, suffering is distress of the person and of his or her family and friends*’. The study results have shown how the suffering of the disabled child affects the whole family network or the other way round. In the case of the Tonga, their suffering is seen to be influenced by the country’s politics, e.g. the withdrawal of food from the communities due to their voting of the ‘Opposition’ etc.

When the participants were asked how they reacted towards the news of the child’s disability, most participants replied; ‘*ndamvwa moyo kuchisa*’ meaning that it was a painful experience. On further probing, the researcher noted that it was the situation (poverty) that was the central issue rather than the disability. Their first thought was; ‘*how do I cope with the child in a situation that is so hopeless?*’ The situation as noted before, does not affect the mother only but the whole family. There is a typical case of suffering. This is seen in the case of the family where the mother was now unable to go out and work to support the whole family as before due to the child’s sickness, hospital and traditional healer visits.

### 5.1 Coping

The study has shown the importance of culture as one of the variables in studies of how families cope with care of a disabled person. In this case Tonga cultural beliefs, (ethno medicine) have been shown to influence their attitudes and behaviour. In their case, disability is seen to be caused by outside influences like witchcraft performed by the extended family or neighbours. This results in the blame of disability not being placed on anyone in the

immediate family and the child being taken care of by the family. Such a situation is likely to result in the family as well as the immediate family helping with child care as noted in the study. The situation is different in a biomedical system where the mother may blame herself for the child's disability and hence fail to cope emotionally with child care.

There was also the relationship between beliefs and attitudes that were noted to be of importance in the family's coping with their disabled child e.g. explanatory models. In the case of the Tonga, the cause of disability can also be attributed to God in the sense that He decides that a '*special family*' will be able to look after the child with disabilities. So, in a way, the family feels that they were chosen by God for the task of looking after the child. This takes place when other explanations have failed or are found unsuitable.

The relationship of previous life experiences and emotions was also noted to be of importance in coping with a disabled child. Previous positive experiences in handling other types of crises had become a source from which they could draw when they got a disabled child. An example of some of these crises was the death of other children who were not disabled. To them, this child was lucky to be alive. In a way, this showed the process of coping through emotional patterning, expectations of life and future, life experiences and actual opportunities. Ingstad (1988) states that; '*culture also provides a frame of reference for critical life events and gives a particular content of meaning to them*'.

On the other hand, the study identified the effects of socio-economic variables on the coping of families with a disabled child. These were seen to be the constraints. These included; poverty, politics, lack of support, lack of knowledge, lack of health care and lack of resources like clean drinking water.

The study identified factors which made families of disabled people worse off. Loss of income was noted when most of the mothers stated that they were no longer working or working less hours due to caring for the disabled child. The children's fathers were also seen to be out of work due to lack of employment in the district. This led to additional costs where money was needed for health care. Exclusion from services like health care and education was noted. There was also the exclusion of mothers from social activities like attending church services or visiting relatives.

There were also the costs incurred by the child's disability. These were the direct costs relating to the disability and costs incurred by those providing care to the disabled child. The extra costs directly related to the disability included such things as medical expenses and equipment (orthopaedic shoes, wheelchairs etc.). The costs of providing care fell on the mothers as well as the extended families. In such a society where there is little support from outside the household, the additional resources (including time) needed because of a disability within the family, had an effect on the household's well being.

The Tonga have a history of suffering since they were evicted from the Zambezi valley fifty years ago. They have been victims of all sorts of oppression and misfortune and have continued to suffer silently. The mothers, with their sick and dying children blame the government for lack of support and resources. The infant mortality caused by malaria, parasitic infections, other communicable diseases and malnutrition were much more prevalent among the villagers. Poverty was the biggest problem that the researcher came across in all the homes visited. Such a situation does not help because it is a well known fact that poverty exacerbates such situations resulting in high infant mortality rates.

The researcher was in the district during the dry season so malaria was not so rife and the information gathered was from the hospital admissions. This showed that 60% of hospital admissions were a result of malaria during the wet season. There was a danger that this was likely to increase during the malaria season of 2005 due to the shortages of fuel and chemicals to be sprayed in the villages. Cerebral malaria is also a cause for concern because this can cause death or disability. A number of children in the villages were noted to have acquired disabilities due to cerebral malaria. They presented with learning difficulties.

Reports of deaths from malaria were reported to the researcher by the mothers in the villages. They stated that their children do not just die from malaria but lack of medicines as well as late presentation to the hospital due to lack of money. Only a few mothers and their under five children had received mosquito nets. The rest were still waiting for them. During the study, the researcher inquired about malaria medication and found that most clinics did not keep it in stock due to shortages of drugs in the district. The researcher and her team made sure that they travelled with the medications for themselves.

Food deprivation and scarcity was the villagers' biggest problem which led to malnutrition among the children. As stated before, this was due to lack of food distribution by the government as well as the barring of food distribution by NGOs. In this case malnutrition is related to the political situation of the country. Drought is one of the causes but as discussed before, a community should not starve because of drought in a given country.

Low birth weight for the newly born babies was a common phenomenon. This was not surprising because the mothers themselves were thin and needed feeding just like their children. A low birth weight, malnutrition, infections and lack of medications are detrimental to the survival of these children. In the case of this study the researcher noted that disabled children were more affected in the sense that many of them were already suffering from opportunistic infections. Coupled with malnutrition and lack of vaccinations, disabled children did not stand a chance. It was a common situation to get to a homestead and being told that the elders had gone to a funeral. The researcher and assistant attended two funerals so as to understand how the Tonga perceives death. The mother of the child was inconsolable and one very old woman was heard to say; *'that is enough my daughter, you will have many more children'*.

The situation here showed that this was a common occurrence and that it was the community's way of life. The old woman showed her previous life experiences of suffering by passing this on to the young mother who was supposed to be strong and look to the future. It was also sad to note the malnourished babies tugging onto a thin strap of their mother's breasts for nourishment.

The parents could not afford to raise money to take the children to the hospital when they needed treatment. Lack of accessible medical facilities and medications as well as the fees barred the villagers from seeking treatment for themselves as well as their children. This was the situation in the three case studies as well. The Tonga did not have a source of income so as to support their families due to high unemployment in the district. The situation can be improved by the government creating jobs for the people so that they become self sustaining.

In Binga, malnutrition is endemic and seasonal. It is seasonal in the sense that during harvest time, the community does reap some crops and have enough to eat for a few months of the year. The Tonga have no source of income to sustain themselves during the dry season when

food is scarce therefore many do starve if they cannot manage to buy or beg. The researcher came across an old lady and her grandson who had not had any food to eat for two days. The little boy asked the grandmother to make him some porridge of ashes and busika (wild sour fruit). This situation shows the degree of food scarcity and malnutrition among the villagers. This was a household of a grandmother and her four year old (non-disabled) orphaned grandson.

Economic hardships make life very difficult for the Tonga. This has resulted in people not managing to buy basic food stuffs like maize meal (staple food) as well as salt in most cases. Such a situation leads a community to seek survival strategies which can in some cases be detrimental to their health. Poverty has put young adults at risk of exposure to HIV. The result of this has been the spread of HIV \ AIDS which the government is struggling to contain. This has led to numerous family problems like the presence of orphans as well as children with disabilities in the homesteads and a high death rate of heads of households who should be taking care of the family. One of the participants was a fourteen year old girl who had dropped out of school to look after her three year old disabled brother with help from an old grandmother. Both parents had died within a year of each other.

The government needs to provide services like 'New Start' centres for HIV testing and counselling. Such services were not available during the study period. A 'new start' team from the nearer town of Victoria Falls had just arrived at one of the clinics to see how they could set up and start HIV \ AIDS testing. The Tonga have heard about AIDS but nothing much has been done. This was disastrous as some areas in Zimbabwe were far ahead with centres for testing and counselling set up a few years ago. One shudders to think what they will find in such a poor community trying to save itself from poverty.

*'Education is the key to breaking the cycle of poverty but the government has thrown away the key'* (The Zimbabwean; 15 – 05 – 06). This was a statement from a Zimbabwe Women's Organisation called WOZA (Women of Zimbabwe Arise). The women had just marched in the cities of Harare and Bulawayo to call for a reversal of the crippling 1 000% increase in school fees. The result was that 185 people were arrested including 73 children. 104 spent the weekend in jails.

WOZA stated; *'The right to education is a fundamental right, both under international and Zimbabwean law. The Education Act clearly states that children have a right to education and that Primary school is compulsory and that parents have a duty to send their children to school. And yet these school fee increases are effectively denying children that basic right'*. This makes sad reading seeing that Zimbabwe used to have the most envied educational systems in the SADC (Southern African Development Countries).

The researcher found the lack of knowledge among the Tonga unacceptable. I remember having to apologise to the driver as well as the research assistant for having shown how shocked I was at the first homestead when I was told that children were not attending school and seeing up to nine year olds still not having started school. The mother narrated her story of poverty and stating that she could not afford fees for the six children as well as food for them to take to school. The distance to the school was eight kilometres one way, and there was the chance of the children being attacked by elephants on the way to and from school.

As stated before (results chapter), the researcher attended a 'parents day' and noted the lack of female students compared to males. This was attributed to parents' lack of school fees which makes them choose to send boys instead of girls. There was also the issue of girls getting married at an early age due to poverty at home. It was also noted that most teachers were not trained, both at primary and secondary levels; and had to cope with large classes, e.g. 40 students or more. This resulted in a high student failure rate. Such a situation makes the disabled child a loser in that an untrained teacher would not be able to effectively manage the child as well as cope with such a big class. The child may have problems getting a desk that suits his height or handicap. The researcher heard of one school that practised inclusive education. This was just one class with children of all ages, which is not suitable at all. Depending on the disability, getting to a school alone would be a task for most of these disabled children due to the terrain as well as other problems.

Nearly every uneducated woman that I have come across in Zimbabwe be it in town or rural areas, expressed a similar yearning for education. It was sad to note that this was not the case with the Tonga. I found that they had no role models for a start and then their poverty has not allowed this '*luxury*' as I am sure they see it that way. As a result I felt that if I were ever in a position of responsibility, I would make sure that women had access to education. The

implication of lack of education is a tragedy especially for women in a community, let alone a matrilineal society. Such a situation needs to be rectified.

The researcher noted that although most of the women were uneducated and, for the most part, illiterate; all of them were aware that the primary cause of infant illnesses and mortality were gastro enteric and other infectious diseases resulting from poverty. Like the Alto mothers in Scheper- Hughes, (1998) study; when asked why in general their children died, their reply was, *'they die because we are poor and hungry and because we cannot afford the medicines'*.

Parental (especially maternal) education, awareness and access to information, and the general level and coverage of primary health care have been found to have a greater (preventive) effect than any specific intervention.

Socio-economic variables were seen to be the greatest constraints to the families. This hampered their coping strategies. The researcher looked at family assets at the homesteads and noted that they did not have much. A few family possessions like goats and chickens (some areas) were noted. A few families had cattle. As stated before, many had died due to drought and some had been sold to offset debts and purchase food for the family. A family of three wives and a dozen children could possess three blankets in total. The rest go to bed with old cloths as covers. They are lucky in that the weather is hot most times of the year except during the wet season when mosquitoes are rife (March – May). Malaria then takes its toll.

Out of the 30 families, one had a small portable battery operated radio and the other had a radio and a solar panel. The rest did not own any exclusive equipment. The wives had a few kitchen utensils whilst the men had a few hoes. A handful of families had ploughs. They all stated that they could do with new or more equipment. Lack of farming equipment as well as animals, makes a family poorer because they are not able to till the land on time. They could not harvest large amounts of food due to the erratic rains, poor farming methods, the unavailability of fertiliser and the money to purchase it. As noted before, elephants do destroy crops in some areas and this makes the villagers worse off for food. Such a situation needs the government's intervention by making sure that wild animals do not get into the homesteads by fencing off the homesteads. Help with tilling the land and loans of seed would be a good

start. Families need to be economically stable so as to manage their families and get their dignity back.

## **5.2 Social Suffering**

As a result of the above situation, the researcher decided to use the concepts of structural violence and social suffering in analysing the situation of the Tonga.

Binga is composed of peasant farmers who were displaced some fifty years ago by Zimbabwe's largest dam. Poverty is the central fact of life for most of the Tonga. To live in their villages is to witness their struggles as they confront the deepening economic crisis that currently grips Zimbabwe. The older inhabitants often blame their poverty on the dam a few miles away that has brought them neither electricity nor water. The Tonga although not educated do understand the cause of their poverty as well as social inequalities. They do understand the '*working machinery*' of the government as their plight.

To a foreigner; poverty, disease, death and more often than not their causes are also seen as problems locally derived - of which it is not the case. People, who do not know the history of the Tonga, have the notion that the Tonga are generally lazy and not capable of helping themselves. The other one is that they suffer from a '*donor dependency syndrome*'. This is because of having had NGOs helping them with food packages for the past few years. The bad part of this is that it often justifies blaming the victim. This is a case of blaming the Tonga, who are viewed as unable to pull themselves together. One needs to get the entire picture, i.e. their history. Such an inquiry must seek to understand how suffering is muted.

The Tonga did not get into the present situation due to their free choice therefore blaming them is not the answer. For example their miserable health care is explained away on the grounds that they have poor motivation and lack health information. The results of this study show that this is neither the case because their suffering is due to abject poverty such that they cannot access the health system either by getting to a hospital or the hospital fee. For families with disabled children, this becomes a constraint as coping with the child becomes much more difficult. As noted before in the cases of Joe and Annie, where the families find it difficult to get them hospital treatment; and sadly the case of Peter who had to die because of his family's poverty. In some cases, the researcher noted that there were no road infrastructures to get to



some of the villages. Access to some homesteads was by foot only, so if anyone needed an ambulance, the chances were that they would die at home if there is no one to carry them to the nearest road. As stated before, the participants laid the blame on historical exigency and unjust social structures.

As stated before (introduction), politics has and is still playing a large part in the lives of the Tonga. There was a shortage of health personnel as well as the lack of a doctor in the district hospital. The rest of the country is experiencing manpower shortages but the Tonga seem to be left out when the few doctors are posted out to the districts. This situation did not seem to be given any priority and the Tonga stated that they were used to being marginalised.

The absence of CBR in any community can be a disaster as noted in the district. The main needs identified for the disabled children were rehabilitation efforts aimed at reducing the immediate effect of the impairment such as physiotherapy and occupational therapy in training in ADL (activities of daily living) and mental stimulation and education. About two mothers in the group had been noted to have attended the rehabilitation department and were given a 'corner seat' to enable the child to sit up. The few who had used the department stated that it had either helped the child or not. One just hopes that one day, CBR will again be revived for the sake of these children as well as disabled adults.

The same political situation was taking place on the '*food front*'. Unlike other villages in the country who were receiving maize or maize meal from the government, the Tonga sometimes went without and when the maize arrived, it would be not enough for the people. However, most people could not afford it. The saddest thing was when the government barred NGOs from entering the district to supply people with food hampers as before. These hampers contained maize meal, beans, cooking oil, dried milk and porridge with nutrients. Targeted activities, i.e. special hampers for pregnant women as well as children to combat malnutrition were put in place. The banishment took place in 2004 and is still the case. This has resulted in untold suffering to the communities. Child malnutrition is now rampant and diseases take their toll leading to death in some cases. There is also the point that severe malnutrition leads to disability, meaning that there is possibly going to be a large number of children with disabilities in the future if they survive. Nobody should have a right to withhold food from another human being.

Natural elements like drought brought suffering to the people. The scarcity of clean drinking water makes life difficult as well as cholera outbreaks. As stated before, the area is ideally not for human habitation but wild life. It could be made habitable by taking water to the people. This would be clean drinking water as well as water for irrigation. Nobody knows what the salty water (Furunga) does to the community's health apart from corroding the children's teeth. The people could be benefiting from the electricity but this has not been possible. According to the Tonga, *'the water and electricity are for the people of the city'*. Wild animals also need their movements curbed to allow people to be able to grow crops and be self sufficient. Deaths from wild animals should not be necessary.

The situation of the participants in this study was echoed by Scheper- Hughes (1998) in her study of the Alto mothers of Brazil. She stated that *'infant and child mortality in the third world is a problem of political economy, not medical technology'*. Binga is an area where malnutrition, parasitic infections and dehydration is an everyday occurrence. Malnutrition, lack of medicines, vaccines, jobs, water and other resources were a result of government policies.

With the scarcity of food, the malnourished mothers still breast fed their babies and gave them whatever else they could find to eat like porridge with salt. Many sought treatment from the traditional healer, and the church. The mothers were not estranged from or indifferent toward their disabled children. Their children were seen as *'persons'* like everybody else and had a right to receive the resources of care necessary to survive. As Ingstad found among the Tswana; she stated, *'To them, their immediate hope is that the child will grow up. A living disabled child may to them be a lot better than two others who die'*.

The Tonga saw the concepts of (Morgan, L. 1998) *'personhood'* and *'human-ness'* very differently from the Alto mothers whose babies had to *'prove'* their worthy of personhood; first by managing to survive, then by exhibiting the vigour and health of one destined to become a functioning member of the community. Scheper- Hughes, (1992) sees the Alto neonates as pre-social persons with the right (and responsibility) to determine whether they will live or die. Scheper- Hughes believes that the relationship between mother and child in the Alto is based largely on a culture of poverty; and addresses the concept of *'mother love'* as being learned behaviour and not biological instinct. These problems are a result of socio-economic and political problems in Brazil.

It was interesting to note the contrast of personal attitudes (towards their babies) between the Tonga mothers and the Alto mothers. Both are caught up in a similar situation but have different attitudes towards their babies. It is sad to note the Alto mothers attitude of not taking care of these '*angels with wet wings don't fly*'; meaning that in the event of the child's death, the mothers should not cry because the baby would not get to heaven. One sees a sad cultural discourse whereby due to a poor socio-economic situation, this notion of the angels wanting to die, made it easier for them to let go (die). On the other hand, the Tonga mothers, because of their belief in the personhood of the child, they still struggled on with coping with care of the disabled child.

Structural violence has already been defined in the introductory chapter. In short, the concept of structural violence is intended to inform the study of the social machinery of oppression. The Tonga lost their homes to the dam and electricity but have not benefited from both. One may then ask what they have or are going to do about it. Kleinman states that the degree to which people can fight back against such infernal machinery has been the subject of much discussion in anthropology. Some have been known to use various forms of '*resistance*'. The researcher is of the opinion that the Tonga are fighting back. This is seen in the way they vote, i.e. voting for the Opposition. This has not impressed the present government; which according to people has resulted in them being sidelined in many issues like the withholding of food by the government as well as NGOs and general infrastructure improvements to the area.

The researcher decided to use structural violence as a way of analysing the situation because one notes the adverse outcomes associated with structural violence as death and illness which in this case is taking place among the Tonga. There is also the violation of human rights involved. Farmer quotes Tacitus who is credited with the aphorism '*They created a desert and called it peace*' meaning that erasing history is perhaps the most common explanation relied upon by the architects of structural violence. The way the problem has been handled is as if they would like the problem to '*just disappear*' i.e. erasing or distorting history.

Farmer, (1998) continues by stating that '*There are certain times, such as now, in which exploring the historical roots of a problem are not a popular process*' (true). One has to take note of the saying; '*People are not that easily fooled – at least not all of them all of the time*'

and that; *time heals all wounds, including those which, never drained properly, are waiting to burst open again, to the 'surprise' of those who have forgotten.*

This study would not be worth talking about if it wasn't for the disabled children who are dying on a daily basis due to their parents' poverty, malnutrition, lack of food, lack of vaccines, lack of spraying of malarial areas, lack of health facilities and access and lack of money to get there and be treated when they need treatment. The '*Binga-power porridge*', i.e. nutritious porridge was available at the hospital but could not be delivered to the village children. Mothers who came to the hospital were not allowed to take home the bag of porridge because of the establishment rules. Free food from NGOs could get to the community but this was not allowed. Without the porridge, the beans, cooking oil, maize meal, soya beans; and a good health care system, the children of Binga will continue to perish.

**Humanitarian action is now needed. It is high time the government owned up to the events that took place those fifty years ago and reparations recommended by the 'international community' acted upon.**

## CHAPTER 6 RECOMMENDATIONS

The researcher feels that the following recommendations will be of benefit to the people of Binga, in order for them to cope with care of children with disabilities.

- ✚ Binga was noted to have a sparsely populated settlement pattern resulting in large distances to cover. The landscape is steep and sandy. This results in difficulty in getting to the nearest clinic, hospital, school, grinding mill, borehole or bus stop. The government needs to provide new road infrastructures that join these essential services to the people. Good road infrastructure will enable help to get to the villagers e.g. food distribution and other services.
- ✚ In the case of drought stricken Binga, access to food is a major issue since the Tonga do not reap enough food to eat all year round. The government needs to make sure that food is delivered to the district and distributed evenly to all, despite their political affiliation. Special food hampers should be given to pregnant women, children below five years old and old people; seeing that malnutrition is a problem in the area. NGOs and other well wishers should be allowed to enter the district and distribute free food hampers.
- ✚ Access to clean drinking water is a major factor that needs to be addressed by the government. For a start boreholes need to be nearer each other so that when people move, they can still access clean water. The government needs to have trained technicians who can repair the boreholes when they break down. The researcher saw a number that had broken down and no one was able to repair them (mostly were put up by the Japanese). Drinking water for livestock is also essential so that the villagers can have food as well as drought power. The answer to this problem lies in getting water from the Zambezi to the people.
- ✚ Improved social services like education, health services and shops are needed. Maternal and child health should be made a priority. The government should see to it first that the district hospital is manned by at least two doctors. The provision of ambulances and fuel should be a priority for emergency cases, i.e. from the

homesteads to the hospital. Medicines should also be available. Hospital fees should be affordable, bearing in mind that only a small population are employed. Children and old people perhaps could be treated free. Primary health care to be strengthened. Mosquito nets to be available to all. Malaria programmes to be strengthened, as well as making sure that villages are sprayed on time.

- ✚ The government has to build more schools in order for the Tonga to be educated. Most children did not attend school due to the long distances as well as other problems. Of the handful secondary schools that are there, a few had boarding facilities. Most of the students were known as 'bush borders' because they had to built shacks to live in during term time at school. This resulted in the few girls attending not finishing school when they got pregnant by the teachers or boys from the neighbourhoods. Some of the parents did not want to send their daughters to secondary school because of this. A shortage of trained teachers is another point that needs to be addressed by the Ministry of Education. This should also include education for disabled children in the district. The government should go back to making primary school education free for all.
- ✚ Growth points need to be improved so as to attract business people to set up shops as well as grinding mills. Women were noted to walk long distances carrying sacks of maize meal for grinding. They would also walk long distances to buy salt and other essentials.
- ✚ HIV \AIDS awareness and prevention campaigns are needed. 'New Start' centres are needed for testing and counselling like the rest of the country.
- ✚ Day centres as well as 'drop in centres' for the young people are essential for educational purposes for the community. These could be extended to e.g. in this case, mothers of children with disabilities to meet as support groups once in a while in the dry season when they are not busy in the fields. The community could be taught different projects which they can embark on so as to sustain their families.
- ✚ Livestock development needs to be strengthened. At present there is a limited 'heifer project' whereby NGOs provide a family with a cow. These are supposed to multiply

and provide the villagers with milk, cash from the sale of milk and cows for ploughing.

- ✚ The district needs rural electrification. This applies to the schools as well as the clinics.
- ✚ Electric fences are also needed to ward off wild animals from getting into the homesteads attacking people and their domestic animals; as well as eating their field crops and food.
- ✚ Community Based Rehabilitation to be commenced again in the district.
- ✚ Job creation by the government is essential. The dying tourist industry needs to be revived. Other new ventures could be started in order for the locals to be employed or become self employed.

The above recommendations are seen to be general in the sense that in the case of them being implemented, life for the Tonga will improve. The study has shown that disability is not something that concerns a single individual alone but the whole care unit. In the case of the *'disabled families'* CBR needs to be implemented in the district so as to help the families cope with care of their disabled children. The government, together with NGOs need to create services for disabled people so as to bring rehabilitation to disabled people where they live and in their local communities. Measures aimed at reducing the impact of disabling conditions and enabling the disabled children to achieve social integration are needed by the community.

Some of these measures could be *'special schools'* as well as integration of children with disabilities into mainstream education wherever possible. The cost of special needs equipment like wheelchairs, orthopaedic shoes, crutches etc. could be subsidised by the government or provided for free in some cases like orphans. Free bus passes should be made available and transport companies made to comply with the request so as to enable families to visit medical specialists in the cities. These are some of the measures that would help families of disabled children cope with care of their children.

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All Africa.com; 9th February 2006-06-11

Zimbabwe Herald; 12th January 2006

## **List of appendices**

### **Appendix 1 The model**

THE DIACRONE PERSPECTIVE;

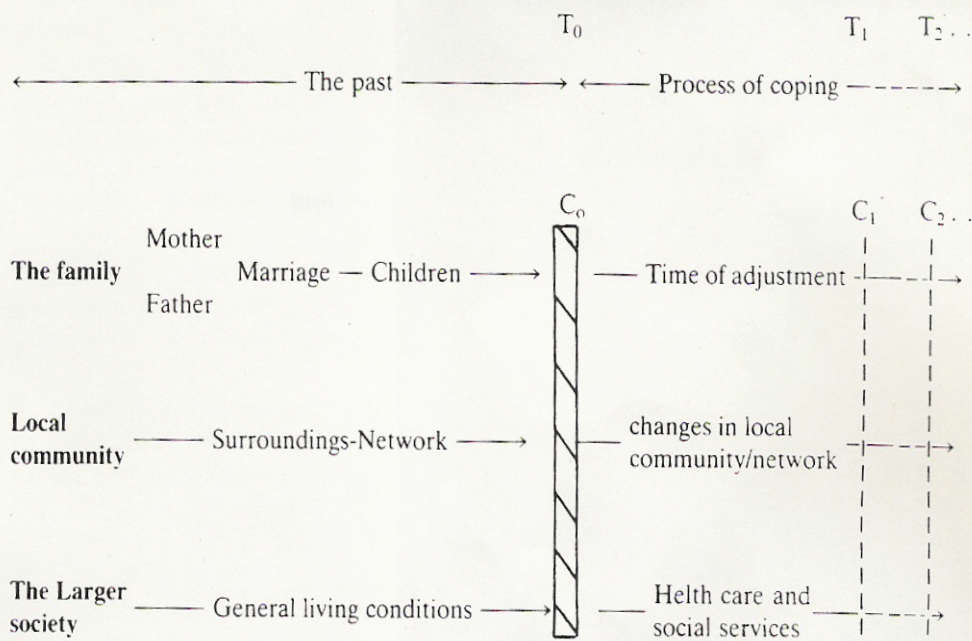
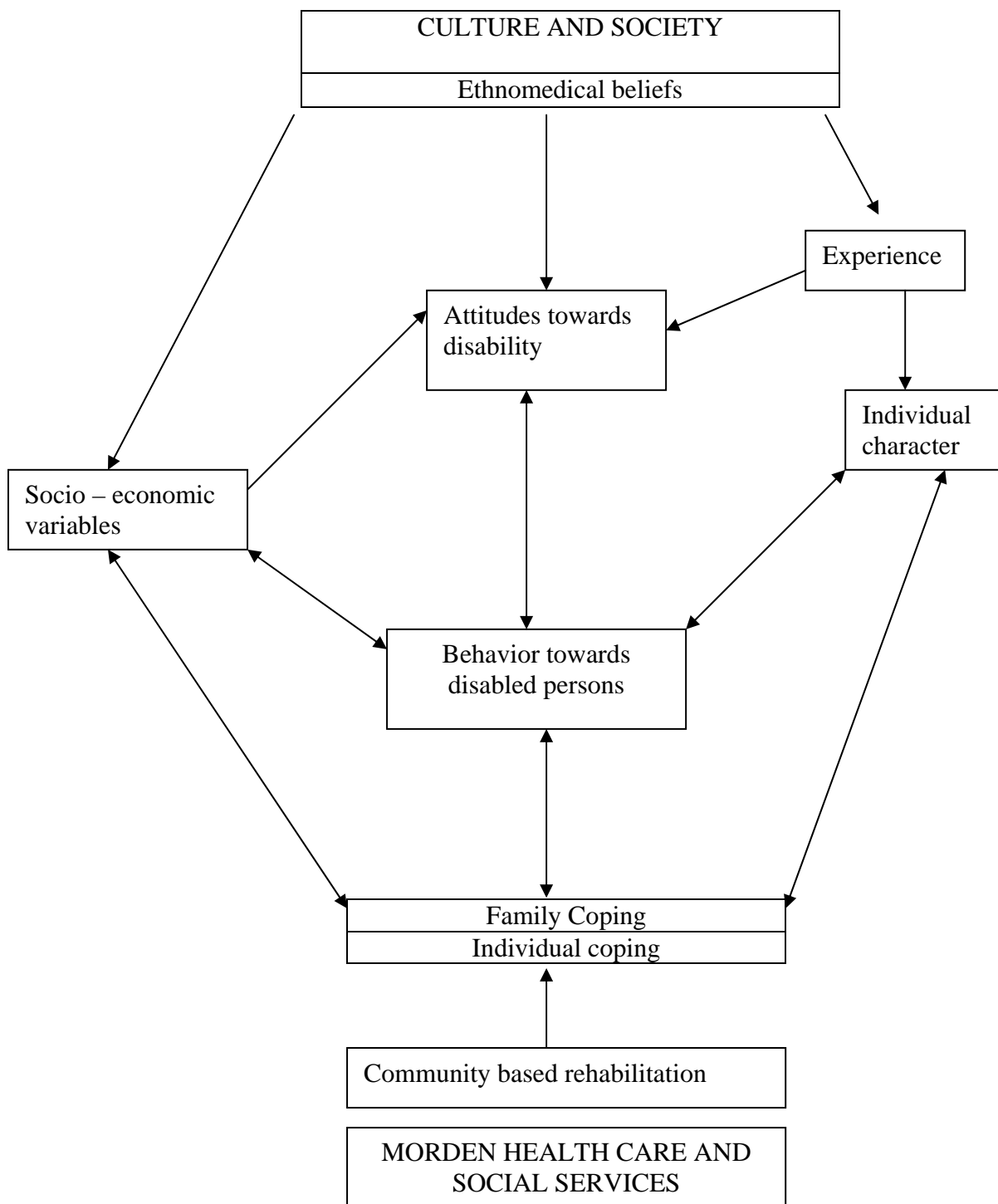


Figure 1. *A model for coping with disability: diachronic perspective\**

\* From: Ingstad & Sommerschild (1983)

From; Ingstad and Sommerschild (1983)

**APPENDIX 2 A MODEL FOR COPING WITH DISABILITY THE SYNCRONE PERSPECTIVE**





## Map of Southern Africa including Zimbabwe



### **Appendix 3 Informed Consent Form - Shona**

University of Oslo

Department of International Health

Institute of General Practice and Community Health

P.O.Box 1130 Blindern

N – 0318 Oslo

Norway.

#### **Information Sheet – Informed Consent Form:**

**Project Title; “Coping Behaviour of Families of Pre – School Children with Disabilities: A Cultural Perspective from Zimbabwe”**

**Investigator:** Ms Jennifer Muderedzi

Address: 6 Southsea Court; 22 Ceres Road; Avondale; Harare.

Tel; 04 – 332171; Cell; 091 367819

#### **Kune Vabereki;**

Ndinokukumbiraiwo kuti muve vamwe veavo varikuzobatsira mukonyorwa kwegwaro iriri.

Sezvo muine vana vakaremara, tiri kuda kuona kuti munokwanisa sei kufambisa upenyu hwenyu pamwechete nevana ava uye pamwe nemhuri yose.

Chinhu chakakosha chaizvo kuti tiwane ruzivo urwu nokuti zvinobastira vamwewo vabereki mukuchengeta vana vavo. Saka munokumbirwa kuti mupe nhoroondo yeupenyu hwenyu musati mava nemwana uyu; paakazozvarwa; uye kusvika nhasi uno. Tinodawo ruzivo rwenyu maererano nekuremara kwevana vakadai mumhuri.

Tinenge tichitapa nhau idzi nechibatamazwi; uye kunyora pasi. Hatisi kuzoshandisa mazita enyu kuitira kuti pasave nevamwe vanozoshandisa nhoroondo iyi zvisina maturo.

Munokumbirwa kuti muve vamwe vevanobatsira mugukuta njere iri; asi kana musinga wirirane nazvo, nokuti hazvikanganise upenyu hwenyu kana hwevana venyu. Kana maona zvakakodzera kubatsira, hapana mari yamunobvisa asi kuti isu tichayedzawo kukubatsirai nepatinogona napo patinenge takagarisana nemi. Hatipe mari kana mushonga; asi kuti tinenge tichingobvunza mibvunzo uye tichiona magariro nemararamiro enyu padururnhuru renyu. Bepa rine mibvunzo richatora maminiti anokwana makumi mana. Hurukuro dzatichaita (Focus Group Discussions) dzichatorawo awa inokwana imwechete.

#### **Appendix 4 Informed Consent Form- TONGA**

Tinokutendai nerubatsiro rwamuchatipa.

Informed Consent Form- TONGA

Signed

Date

Witness

Ndamvwisisisya kuti Project eyi yambanzi nkinkako ndayanda kugwasizya

Kusandula mibuzyo itanobuzigwe amwendelazyi. Tendajatwa amanguzu pe kuti nchite

Booboo.

### **Appendix 3 Informed Consent Form - Shona**

University of Oslo  
Department of International Health  
Institute of General Practice and Community Health  
P.O.Box 1130 Blindern  
N – 0318 Oslo  
Norway.

#### **Information Sheet – Informed Consent Form:**

**Project Title; “Coping Behaviour of Families of Pre – School Children with Disabilities: A Cultural Perspective from Zimbabwe.”**

**Investigator:** Ms Jennifer Muderedzi

Address: 6 Southsea Court; 22 Ceres Road; Avondale; Harare.

Tel; 04 – 332171; Cell; 091 367819

I hereby request you to participate in this study which involves research, looking at ways of coping with your child with disabilities. It is important to gain an understanding of how you are managing with taking care of your child as well as with life in general. This research will help in providing more information to enable other families of children with disabilities to cope under these circumstances.

I would like to find out a number of things from you concerning your opinions and experiences on this subject. The information, collected through audio tapes and taken note of in a book (after obtaining permission from every participant.) It will only be serially linked by codes and not real names; all data collected and the instruments used will only be accessed by the researcher and her assistants; all the information obtained will be handed confidentially and shall not be used for any other purposes other than for the report.

Participation in the study is voluntary, with no consequences for not being involved. Therefore, if you do not wish to participate in the study, be assured that this will not affect your ability to access the usual services you currently get or expect to obtain from your health provider now and in the future. In the event that you agree to participate, you are also free to end your involvement at any time of your choice, if you feel like doing so.

There may be additional costs arising from this study. However, the researcher will cover all expenses related to your participation. This research will not involve the use of drugs or other medicines, as the methods of gathering data are only through the use of interview guidelines as well as observations, which are well defined. The interview is expected to last for 45 minutes. For those participating in Focus Group Discussions, the expected time will be about one hour and thirty minutes. For those willing to have the researcher live with them for a day or so, the researcher will help where possible.

Kindly sign here if you have no objections to participating in this study.