

Background and Purpose of Study

This study was commissioned by UNICEF to analyse the situation of children with disabilities in Zimbabwe. Children with disabilities in the country live under especially difficult circumstances and are vulnerable as they live with negative attitudes, beliefs, labels and stigmas that militate against them. They face challenges and problems that ordinary children do not experience. They have limited access to facilities and their fundamental rights, such as education and health, are often compromised. Most services for children with disabilities are provided for by non-governmental organisations as charity. Disability has not been put on the national agenda as part of development and is viewed largely as charity or as a social welfare issue. Children with disabilities are therefore caught in a difficult situation hence this study to analyse their situation.

Defining the Population of Study

The word disability is subject to a wide variety of interpretations. A study of contemporary literature on the subject yields many different definitions based on either medical, legal, sociological, psychological and even subjective emphasis. Ingstad and White (1995) point out that attempts to universalise the category of disability runs into conceptual problems because such definitions should take into consideration the social and cultural contexts. However, the World Health Organisation defines disability as “*any restriction or lack of ability to perform an activity in a manner or within a range considered normal for a human being.*” (WHO, 1996).

In a study of this nature, a specific definition needs to be adopted as this helps to focus on the population of study. For instance, the National Disability Survey of Zimbabwe (Department of Social Services, 1982) came up with a working definition of disability that incorporated both clinical and functional aspects and ramifications, as well as highlighting pronounced disability its self. Disability was defined as “*a physical or mental condition, which makes it difficult or impossible for the person concerned to adequately fulfil his or her normal role in society.*” (Department of Social Services, 1982 p 8)

More recently, the Disability Act of Zimbabwe (revised edition: 1996) defined a disabled person as “*a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society.* (Disabled Persons Act Chapter 17:01 revised edition, 1996 p 51).

It is important to note that disability is multi-dimensional and that disability in one dimension does not necessarily imply disability in other categories (Central Statistical Office, 1997). Many people with disabilities are victims of such overgeneralizations especially the assumption that disability is equal to inability. In this study, children and adolescents within the following disability categories were studied:

- Deaf and hard of hearing (hearing impaired)
- Blind and low vision (visual disability)
- Mental disability (mentally retarded)
- Motor and physical disability (physically disabled).
- Multiple disabilities

These were the main disabilities covered in most of the literature (e.g., Hardman, Drew & Egan, 1996; Hunt & Marshall, 1994; Ysseldyke & Algozzine, 1995), in the annual reports of Zimbabwe Government Ministries (e.g., Annual Reports of the Secretary of Education, Culture and Sports) and in the definitions given above.

Prevalence of Childhood Disability

The study on Children in Especially Difficult Circumstances in Zimbabwe (CEDC) (UNICEF, 1997) found an estimated 150 000 children with disabilities in the country. Estimates on disability depend on what is considered as disability, on how severe an impairment must be before it is considered disabling, and on how categories are

implemented in the actual gathering of data (Ingstad & White, 1995). The estimates given in the CEDC study could have been influenced by such factors. Renker (1982) warns that although a number of disability surveys have been carried out in developing countries, we can still make only a qualified guess about the statistics. An epidemiological study involves cultural factors (Johnson, 1991), and cultural factors are involved in attempts to count cases of disability (Ingstad & White, 1995). These differ from culture to culture.

The Inter-Censal Demographic Survey (ICDS, 1997) recorded a total of 218 421 people with disabilities in Zimbabwe. Of these, 56 % were male and 44 % were female. Seventy-five percent of the people with disabilities lived in rural areas while 25 % lived in urban areas. The total number of people with disabilities was estimated to be about 2 % of the total population of Zimbabwe (ICDS, 1997). In the study, 57 232 children with disabilities (0-19 years) were identified in the country. Of these, 45 228 (79%) were from rural areas while 12 004 (21%) were from urban areas. The ICDS is silent on the number of children with disabilities attending school although it has a full section on education. It appears there is need to carry out a more comprehensive disability survey as part of a census process. There are no definite comprehensive statistics of people with disabilities at the moment.

Causes of Disability

The Government of Zimbabwe carried out a national survey of disability in 1981 to “ascertain the extent, nature, main causes and impact of disability in the country” (Jackson, 1993:1). This data is out dated and the survey itself had many flaws (e.g., it invited people with disabilities to volunteer to go to a central place to register). However, this survey remains an important study in that it was the first such survey to be done in Zimbabwe and it provided a database on which to base planning for the nation. In the survey, childhood disability (0 –15 years) accounted for 53 percent of all disability in the country (140 000). Average disability occurred between 0 – 4 years and this accounted for 41 percent of the disability.

According to the National Disability Survey of 1981 it was difficult to say accurately what the causes of disability were especially in rural areas. For example, in response to the open-ended question “What caused your disability?” Seventeen thousand (17 000) people answered that witchcraft was involved (Department of Social Services, 1982 p 31). This is a very large number and there is no reason to believe the situation has since changed.

The following statistics were given as the causes of disability:

Table 1-: Causes of Disability

Causes	0-4 years (%)	5-15 years (%)
Disease	61.5	60.1
Accident	9.6	23.0
Abnormal birth	7.3	4.1
Malnutrition	9.6	1.7
Heredity	1.9	2.8
War	1.9	5.1

(Adapted from Department of Social Services, 1982:59)

The group discussions were held as follows:

- Deaf children and adolescents: Morgenster School For The Deaf was used for this group.
- Blind and low vision children and adolescents: Blind children and adolescents at Copota School for The Blind were used for this purpose.
- Children and adolescents who are physically disabled: St Faith Mission was used for this purpose.
- Three parental focused group discussions were held: one at Mhangura Mine representing the mining community; one at Gokwe representing the rural community which was made up of Shona caregivers; and one in Bulawayo representing the urban community which was made up of Ndebele care-givers.
- Due to the complexity of the problem of children and adolescents with mental disabilities, it was not possible to conduct interviews and use questionnaires. Chances were that some would give unreliable information. Instead observations were made of these children in classroom situations and in their homes.

The main causes of disability according to the survey were diseases, accidents and malnutrition. War was given as one of the causes of disability (1.9%). This was the case then (1981) because Zimbabwe was just coming out of a war situation. This aspect of causes of disability has since changed.

The ICDS (1997) identified the general causes of disability in Zimbabwe to include congenital birth defects, war, accidents, diabetes; and preventable diseases such as measles, polio, and TB. The malnutrition of a pregnant mother leads to growth retardation of the foetus, malformations and poor brain growth of foetus. Some causes of sight problems in Zimbabwe are cataracts and glaucoma. Other causes of disability are maternal rubella, otitis media and meningitis. Children infected by HIV/AIDS and those who are terminally ill because of any other causes are classified as disabled (Hardman et. al., 1996). Pregnant mothers infected by HIV/AIDS and are constantly ill and at risk of giving birth to children with disabilities.

Scope and Methodology

The study was carried out throughout Zimbabwe covering urban areas (Harare, Kadoma, Gweru, Masvingo, Bulawayo, Mutare), rural areas (Rusape, Gokwe, Nkwali, Nkayi, Murehwa, Musami, Mudzi), mines (Mhangura and Alaska), commercial farms (Mhangura and Chinhoyi areas) and peri-urban areas (Ruwa and Domboshava). It looked at caregivers of children and adolescents with disabilities, children and adolescents with disabilities themselves and officials of institutions of children with disabilities.

A literature review was undertaken, and issues arising from the review were validated during field research.

The study used a triangulation of methods to assess the extent of the problem and to analyze the causal factors. Three structured questionnaires were used to collect data: one was for the care-givers, one for the children and adolescents with disabilities and the other one was for officials of institutions and integration units (see Appendixes I, II, and III, respectively). Because some research participants were illiterate, the researcher and his assistants read the questions and wrote the answers as care-givers gave oral replies.

The study also used focused group discussions, interviews of key informants and observations to collect data. Six focused group discussions were held. The number of people per group varied between six and ten participants and the discussions were led by selected research assistants who had been trained to do so, while the other research assistant and the researcher took detailed notes of the discussions.

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- Due to the complexity of the problem of children and adolescents with mental disabilities, it was not possible to conduct interviews and use questionnaires. Chances were that some would give unreliable information. Instead observations were made of these children in classroom situations and in their homes.
- Data was analysed using both quantitative and qualitative data methods. Answers from the three questionnaires were coded for easy capturing into the computer and then analysed using the SPSS computer statistical package. This was used to obtain frequencies and descriptive statistics. Qualitative data from the questionnaires, interviews, observations and focussed group discussions were categorised into themes and analysed to find the main issues. These were described in detail to give a holistic picture of the results.

One hundred and seventy care-givers participated in the study. Of these, 32 (19%) were male and 138 (81%) were female. Forty-six (27%) were from urban areas, 58 (34%) were from rural communal areas, 36 (21%) were from mines, 20 (12%) were from peri-urban areas and 10 (6%) were from commercial farms.

A total of 293 children and adolescents with disabilities answered the structured questionnaire. Of these, 164 (56%) were male and 129 (44%) were female. One hundred and thirteen (39%) had hearing disabilities, 98 (33%) were visually handicapped, and 81 (28%) had physical disabilities while only one had multiple disabilities. Twenty

children with mental disabilities were observed in classroom situations and four were observed in their homes. Twenty-eight officials of institutions that service or look after children and adolescents with disabilities, participated in the study. They answered the questionnaire and four of them were interviewed.

Seventy-two percent of the care-givers participating in the study had only one child with disabilities that they cared for and 27% cared for two children with disabilities. In the focused group discussions, care-givers said they had two basic constraints when caring for children with disabilities, namely time and money. Parents, particularly mothers, needed time to meet their other responsibilities. They had many chores to do for the family. Yet the more severe the disability or the more the number of children with disabilities in the family, the more time mothers needed to look after the child/children with disabilities and at times to the detriment of other children in the family.

Observations made in houses and classrooms of children with mental disabilities and those with multiple disabilities found that the care-givers spent more time caring for these children than they did with other children in the family. Some of the children with disabilities did not have basic survival skills like feeding themselves, moving to the bathroom, toilet, etc. This required that the care-givers care for the children twenty-four hours a day. The situation was complicated further for 28% of the care-givers as they had more than one child with disabilities.

Family Support

One hundred and forty (84%) care-givers did not receive assistance from their families when they realised that their child was disabled. Twenty-eight (16%) received support from members of their families when they realised their child had a disability.

Of those who received support, it came mainly from grandparents particularly maternal grandmothers. This was corroborated by evidence from the questionnaire on children. When asked whether their grandparents liked them, 55% of the children felt that their paternal grandparents liked them compared to 73% who thought their maternal grandparents liked them. Maternal grandmothers gave support to the family of a disabled child primarily to support their daughter who carried the blame of giving birth to such a child. Also, maternal grandmothers sympathised with their inexperienced daughters because of the overall responsibilities associated in caring for children with disabilities. This is why they were quick to provide support in such situations.

On the other hand, most of the caregivers (84%) did not receive any support from both their nuclear family and the extended family. When asked to explain why this was the case, the following were given as explanations.

- Some relatives saw the birth of a child with a disability as a taboo that brought bad omen to the family. As a result, they did not want to be associated with the situation. When probed to explain further during group discussions, the care-givers noted that family members came to their support if there were family rituals being performed that would cleanse the child with the disability, thus removing the bad omen. This suggested family members were supportive of not the child with the disability, but rather the desire to eliminate the disability itself.
- Most of the relatives of the husband's side blamed the disability on the wives. Care-givers in the focused group discussions related stories of sour relationships between the mother-in-laws and their daughter-in-laws with disabled children. Most mother-in-laws were said to be angry with daughter-in-laws who brought disabled children into the family. They therefore gave little support in such situations.
- Some care-givers, particularly those in the urban areas, said family support was not forthcoming because people were too busy with their lives. They had no time to take care of someone else's problems particularly in these harsh economic times.

This question was probed further during interviews. When asked if they thought it was important to revive the traditional family support structures or not, most care-givers wanted the support structure revived. They realised that family support structures were important not only on issues of disabilities, but in many other circumstances.

- Some care-givers felt both in the questionnaire items and focused group discussions, their family members did not give them support because they did not know how to support them. They observed that most of their relatives were uncomfortable when confronted with children with disabilities. Even when their relatives

visited them they noticed the tension. The more severe the child's disability was, the more uncomfortable the relatives were in associating with such children, let alone assisting in their care.

- This data was collaborated by the data from the children with physical disabilities and focused group discussions. They felt strongly that their relatives were uncomfortable dealing with them. The relatives did not know how to deal with children with disabilities. Adolescents with disabilities were particularly concerned that relatives wanted to do everything for them. They viewed them as incapable. They were even embarrassed to go and ask.
- The focused group discussions of the caregivers in rural areas, particularly in Gokwe, stressed the fact that most fathers of children with disabilities did not participate in caring for their children with disabilities. The fathers did not want to be associated with the child with disabilities and left everything to the mother. In some cases, fathers behaved as if the child was not theirs.

Community Support

One hundred and fifty four (91%) caregivers did not receive any support from their communities on how to care for their child with disabilities. One percent got support from support groups of parents of children with disabilities, 6% were assisted by churches and 2% received support from non-governmental organisations. Care-givers in the focused group discussions in all the three groups required support from their communities. Unfortunately, this support was not forthcoming. No one was informing the community on the need for such support structures to be put in place. Traditional structures in the villages had nothing to do with people having disabilities. When asked if chiefs, kraal heads and the Zunde concepts were helping them in caring for their children with disabilities, the care-givers in the focused group discussions responded negatively. However, they saw the potential of using existing traditional, administrative and local service structures to lobby for support. They noted that there was need for sensitising and making the community aware of their responsibility towards the disabled.

Education

Fifty-four percent of the care-givers (92) who participated in the study had their children with disabilities in school while 46% (78) did not.

Authorities of institutions that teach children with disabilities noticed that school enrolment, particularly of blind students at boarding resource units, were decreasing. Some units had actually closed. Children simply stopped coming to school, and many left behind large bills of unpaid school fees. The boarding fees for these children could not longer be afforded.

The care-givers of children with severe to profound multiple disabilities were the bulk of the 46% that did not have their children with disabilities in school. These were the children who were not mobile. Some children were unable to sit on their own, others were bed-ridden, and some required a constant change of clothes because they soiled themselves. The care of these children was very demanding and care-givers were unable to source school placements or receive any assistance for these children. There was only one institution in the country that taught such children and it was completely full.

The other group of students with disabilities included a large number out of school children who suffer from severe mental disabilities. Most caregivers of such children in the study wanted their children in such circumstances to go to school. Some of them had been assisted by Schools Psychological Services to get places for their children at schools/units of children with mental disabilities. Unfortunately, all such schools in Zimbabwe fall under one organisation and according to the parents in the focused group discussions, the fees were too expensive. Although their children were offered places, they did not take them up. In addition, schools for such children were all in urban areas leaving children in the rural areas, mines and farms without such facilities.

Given a choice, 47% of the care-givers said they preferred that their disabled children go to their local school in the neighbourhood, together with their siblings. Eighteen percent preferred them to go to a regular boarding school where they integrated with non-disabled children, while 34% preferred that their children with disabilities attend a special boarding school for the disabled only. Only one percent preferred to relinquish their children with disabilities be institutionalised and allow the institution to assume total responsibility for the child.

Asked to explain why they preferred the choices they made, care-givers provided the following:

- Care-givers who preferred their children to go to the local school in the neighbourhood wanted to be near their child. Some of the parents described their child as a sick person (*murwere*) and needed to be monitored by them. Others felt their child would benefit more by learning with non-disabled children. They said integration offered the child with disabilities the challenge and opportunity to lead a normal life.
- Others still did not want their children with disabilities to go to the local school because most local schools did not have specialist teachers for such children. School heads and the teachers in the schools were also not very comfortable with the children's presence and local schools did not have money to buy the equipment and supportive devices required by children with disabilities.
- Care-givers who preferred their children to go to special schools especially boarding ones wanted their children with disabilities to be among other children of similar conditions and to be taught by specialist teachers. They saw special schools as having both the human and material resources to be able to teach their children more effectively.

Analysis of Causal Factors

The analysis of causal factors deals with issues arising out of the literature review, some of which were validated during field research. Figure 1. depicts the framework utilised to analyse causalities at various levels.

The other policy of interest to this discussion is the Zimbabwe Psychological Practices Act (Revised 1988) which advocates for the development of individualised programmes for persons with disabilities and the placement of special needs children in the least restrictive educational environment. In other words, the Act advocates for the integration of children with disabilities in ordinary schools whenever possible (least restrictive environment). This position is well supported in the literature and is in line with the normalisation principle (Wolfensberger 1972; Flynn & Nitsch, 1980) and the concept of inclusive education (Vlachou, 1997). In practice though, many children with disabilities are still institutionalised in special schools.

Some children with disabilities manifest a sickly, unkempt appearance, are usually out-of school, begging in streets, buses and in homesteads, and normally lack support equipment and devices, such as hearing aids and wheelchairs.

Immediate Causes

Lack of Support Equipment and Devices (e.g. wheelchairs)

Caregivers, especially the mothers, had to carry the child on their backs. As the children grew older and bigger it became very difficult for the mothers to carry the children around. Most of these children did not have wheelchairs in their homes and their care-givers did not have the money to buy the wheelchairs. One of the care-givers was so desperate that she persistently asked the researcher to give her work so that she could manage to buy her child a wheelchair and send her to school. Parents of children with severe to profound multiple disabilities felt their children's condition required that they be hospitalised. To them, using the local school was out of question. They preferred schools with hospitals such as the one in Bulawayo, which unfortunately it is the only one in the country and is always full.

Poor child care and supervision practices, including not taking children for immunisation and poor nutrition, as well as poor maternal health during pregnancy (STI; HIV/AIDS), were identified as immediate causes. Other factors included inadequate and in some cases, poor management of family resources, limited access to health, education and counselling services.

Underlying Causes

Negative Attitudes and Beliefs

In both the review of literature and the field validation, **attitudes, beliefs and stigma** that are negative to children and adolescents with disabilities featured prominently. The Shona and the Ndebele people's cultures hold negative beliefs on the causes of disabilities. For instance, disability was associated with witchcraft, promiscuity by the

mother during pregnancy, punishment by ancestral spirits or by God, evil spirits, etc. These negative attitudes handicap further the people with disabilities. Generally, society reacts with horror, fear, anxiety, distaste, hostile and patronising behaviour towards children and adolescents with disabilities. This leads to isolation, discrimination and prejudice against some of them.

Traditionally and culturally, the Shona and Ndebele people held negative attitudes and beliefs towards disability and the child with disabilities. Even today these attitudes are still prevalent and strong, though at times salient. Often disability is associated with witchcraft (Department of Social Services, 1982), promiscuity by the mother during pregnancy (Addison, 1986), and punishment by ancestral spirits or directly by God to the family or the parents of the child with a disability (Jackson, 1990). Some people with disabilities are seen as possessed by evil spirits. Deaf people's speech defects perpetuate this perspective (Chimedza, 1999). Also, it is generally felt that one should not laugh at a person with a disability or the curse may be transferred to you (Barnatte & Kabzems, 1992). Furthermore, pregnant women should not look at or associate with people having disabilities or they may give birth themselves to a child with disabilities. Similar beliefs and attitudes towards disability have been found elsewhere for example: Nigeria (Onwegbu, 1977), Zambia (Phiri, 1979), Bangladesh (Ahmadulla, Hafizul & Shamshir, 1981) and Pakistan (Miles, 1983).

According to Coleridge (1993), it is attitudes that disable. Society's attitudes towards people with disabilities can handicap the individual. Generally society reacts with horror, fear, anxiety, distaste, hostility and patronising behaviour to people with disabilities. This leads to discrimination and prejudice against these people due to many associated myths and stigmas. Coleridge (1993) gives the following quotation from an interview he had with a blind person in India, Samir Ghosh. He says:

"I take the attitude that people are nice, people are good. But I think human beings tend to bank on their bad experiences, rather than their good experiences. We tend to judge the whole human race on just one or two bad experiences. For example, I once went into an office to ask for an address, and they told me to get out because they thought I was a beggar".

For many disabled people, rejection is catastrophic. It provokes despair and retreat. And yet, societal attitudes towards people with disability are mainly of rejection. In some cases, people with disabilities go through some traditional cleansing ceremonies and rituals. We give an example below of the experiences of the late Ranga Mupindu who was himself disabled, and was a leader and activist in the disability movement in Zimbabwe. We quote his words from Chimedza and Peters (1999):

"As a result of these experiences, there were a lot of factors which made me really critical of our culture, including conflicts within our culture. For example, my grandmother thought that in order to be secure, I would need to be cleansed, and the experience was very nasty. I remember even my mother was telling me it was the only way. I was taken up to a mountain and I was left overnight on the mountain on my own. They were to collect me the following morning. Traditional rituals were performed. It was expected that was the way of really helping me out. It was very terrible (Chimedza & Peters, 1999)."

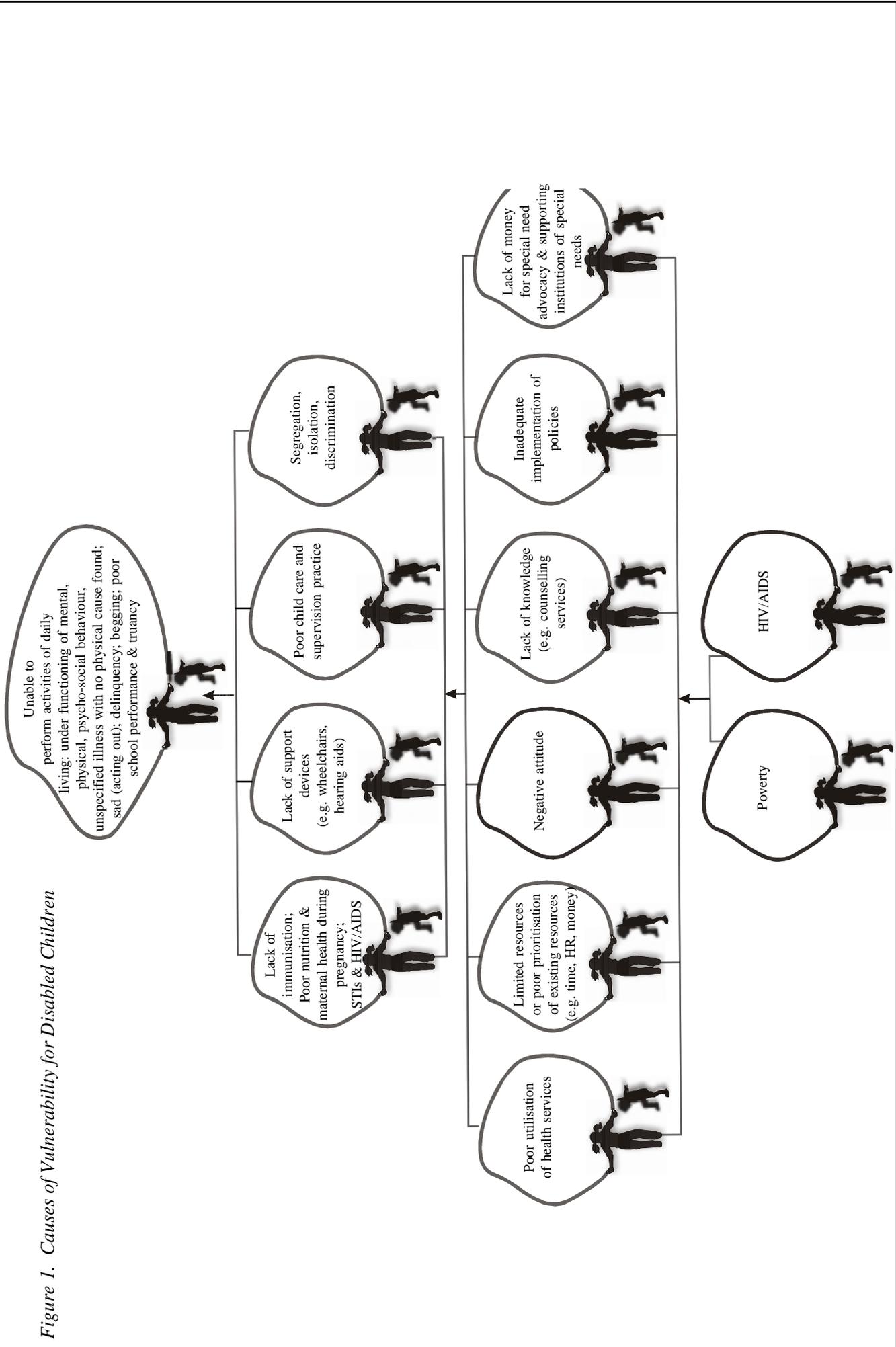
Poor utilisation of health services, limited resources or poor prioritisation of existing resources (e.g. time, money, human) and lack of knowledge and counselling services were also identified as underlying causes of disability.

Children with Disabilities and Education Provision:

The Schools Psychological Services and Special Education section of the Ministry of Education, Culture and Sports is responsible for providing education for children and adolescents with disabilities. It specifically runs programmes for children with the following disabilities: mental, physical, visual, hearing, speech and language and specific and general learning disabilities (Annual Report of the Secretary of Education and Culture, 1995 presented to the Parliament of Zimbabwe 1998).

The Education Statistics (1996), gives the total number of students in schools to be 3 244 140. It does not say how many of these students have disabilities. However the study on Children in Especially Difficult Circumstances in Zimbabwe (UNICEF, 1995) puts the total number of children with special educational needs to be 19 096. The breakdown of the figure was as follows: children with major disabilities (mentally retarded, blind, deaf, and physically disabled) numbered 4 247, children in special classes were 7 898 and children with disabilities "wildly"

Figure 1. Causes of Vulnerability for Disabled Children



integrated in ordinary schools without support were 6 951. The total comes to 19 096. Considering that the ICDS (1997) registered 57 232 children and adolescents (0-19 years of age) in the country, we can estimate that 33 percent of children and adolescents with disabilities in Zimbabwe are in school. The rest (67%) are not in school. The National Orphan and CEDC Enumeration Report (December 1999) says school enrolment figures for children with disabilities reveal a high level of non-enrolment. Among those aged between 7 and 12, in a sample of 1327, 40.9% of the males and 44.6% of females were not enrolled. For this age category, the non-enrolment figures are more than four times those for all children in especially difficult circumstances. The exercise found out that among children in the 13 to 16 age range, 47.2% of boys and 57.7% of girls were not enrolled in school. Among those aged 17 to 18 years, 69.7% of males and 84.9% of females were out of school.

The Situation Assessment and Analysis of Children and their Families (UNICEF, 1999) observed that social stigma attached to disability, lack of awareness of special schooling possibilities and entry barriers resulting from tuition fees or transportation costs, combine to limit access of disabled children to specialised schools and rehabilitation. According to the same analysis, virtually all disabled children receive inadequate formal education, the vast majority receive no education at all, and girls and rural children suffer the greatest losses, spending their days idly in the company of care-givers who are non-responsive and likely to regard them as a burden.

This discussion of provision for education for children and adolescents with disability would not be complete without reviewing the legal instruments in place to safeguard the education of these students in the country. The Zimbabwe Education Act of 1987 (revised in 1996) has a non-discriminatory clause in its provision for education to the nation. Section 4 (paragraph 2) of the Act states that:

“No child in Zimbabwe shall be refused admission to any school on the grounds of race, tribe, colour, religion, creed, place of origin, or social status of his or her parents.”

The Act is silent on discrimination due to disability or one's abilities. In other words, the rights of children with disabilities to education in Zimbabwe, is not protected by law. In other countries, education for children with disabilities is protected by law (e.g. U.S.A. Individuals With Disabilities Education Act 101- 476) (Hardman et. al. 1996). There is therefore a legal gap in the provision of education to children and adolescents with disabilities. In the absence of such an instrument, it is not surprising that only 33 % of the children with disability have their right to education met and are in school.

The other policy of interest to this discussion is the Zimbabwe Psychological Practices Act (Revised 1988) which advocates for the development of individualised programmes for persons with disabilities and the placement of special needs children in the least restrictive educational environment. In other words, the Act advocates for the integration of children with disabilities in ordinary schools whenever possible (least restrictive environment). This position is well supported in the literature and is in line with the normalization principle (Wolfensberger 1972; Flynn & Nitsch, 1980) and the concept of inclusive education (Vlachou, 1997). In practice though, many children with disabilities are still institutionalized in special schools.

Basic Causes

Poverty

Of the 170 care-givers who answered the structured questionnaire in this study, 12% were in gainful employment and had steady income, 1% had businesses while 87% were unemployed. The 87% not employed did not have any other steady income to support their families with. During focused group discussions, care-givers expressed concern that disability was expensive and they did not have the money to meet its demands (constant medical care, purchase of support devices such as wheelchairs, hearing aids, tests, etc.). Access by disabled children to these basic requirements was worsened by the fact that government did not provide free services.

The fact that most care-givers of children with disabilities are of a low income status was collaborated by the data from the children with disabilities when asked how many thought their care-givers could:

- Afford to pay their school fees. Only 64 (22%) were in the affirmative.
- Pay for their medication. 88 (30%) were positive.
- Pay for their food. 85 (50%) said the parents could afford.

Not only are the care-givers not in gainful employment, but their children with disabilities have themselves concluded that their parents/care-givers have no means to pay for their basic needs.

One of the main reasons why the charity model is common as a service provision to people with disabilities is that there seems to be a positive co-relation between poverty and disability. There is likely to be a higher incidence of disability among poor people than among rich people. Also, there is likely to be a higher incidence of poverty among people with disabilities than among non-disabled people. The reason why there is likely to be a higher incidence of disabled people among poor people is because poor people cannot afford medical treatment of some of the diseases that cause disability. Ignorance/lack of knowledge also plays a part. There is need to break the cycle of poverty and disability. This is only possible if society makes available to people with disabilities education programmes and skills for them to participate in the national economy.

Role and Responsibility Analysis

The question was posed asking who the primary care-giver and duty-bearer was of the child with disability in their family. Twenty-two percent of the care-givers said it was both parents, 53% felt it was the mother, 2% felt it was the father while 23% said it was other relatives, mainly maternal grandparents.

In the focused group discussions, all groups agreed that mothers were the ones looking after the children with disabilities and not the fathers. This was like a given responsibility for mothers. Fathers supported from a distance. In some cases, fathers were not even prepared to spend money on these children.

When asked further as to whether the caregivers felt it was their responsibility to look after these children or not, 95% of the caregivers felt it was their responsibility, while 5% did not.

On the question as to who had the authority over the children with disability in the household, 9% said it was either parent, 19% said it was the mother, 52% felt it was the father and 20% believed it was other members of the family.

When the same issue was discussed in the focused group discussions, the participants (mostly mothers) felt that the fathers' authority over children with disabilities was mostly theoretical. In practice, mothers were making decisions on what to do with their children with disabilities because fathers did not want to be involved. However, the fathers of these children want to exercise their authority and make decisions. In a way, for children with disabilities there was role reversal. Mothers, although they may not be the head of the household, made decisions for their children with disabilities.

Persons with disability tend to be perceived by the non-disabled as lacking in clear social role functions. This phenomenon has been described as role marginalisation (Devlieger, 1998; Mpofu, Thomas & Thompson, 1998) or social liminality (Murphy, 1990). For example, the marginalisation of persons with disabilities in sub-Saharan African societies is suggested by wide spread use of the word "lema" or "rema" (i.e. become heavy, failure, experience difficulty or foolishness) to refer to physical or mental disability (Burch, 1989; Devlieger, 1998; Mpofu, 1999). In other words, having a disability is considered to make an individual incapable of many roles. Moreover, in sub-Saharan Bantu languages, the word "lema" or "rema" is prefixed by the object or animal - referent "ki," "chi" or "isi" (for "it") as in "kilema" (e.g. Kiluba, Kisanga, Songye languages: Angola, Congo, Zambia), "chirema" (Shona language: Zimbabwe, Mozambique) or "isilima" (Ndebele/Nguni languages: Zimbabwe, South Africa, Malawi, Tanzania) or human - referent "mu" as in "mulema" (e.g. Kiluba, Kisanga, Songye languages). Therefore, the sub-Saharan African languages consider a person with a disability as the borderline between a human being and an animal (Devlieger, 1998).

Role marginalisation may be higher in adolescents and females with disabilities than in children and males. Native Zimbabwean cultures have higher role performance expectations for males than for females (Mpofu, 1999) which bias could further marginalise females with disabilities.

• Role of Parents

The birth of a child with disability in a family raises in parents feelings of shock, disbelief, denial, anger, resentment, depression, despair, guilt, shame, etc (Hardman, et, al., 1996). According to the Situation Assessment and Analysis of Children and their Families (1999) parents may even believe the child to be a curse, so they may hide

the child as a way of coping with the affliction and retaining social equilibrium. The parents are likely to subject the child with a disability to neglect, abuse and not give the child parental love which is essential for any child's psychological development.

• *Role of the Extended Family*

The role of the extended family in taking care of the child with disabilities cannot be ignored. Many disabled children are left in the communal lands in the care of maternal grandmothers while the mother seeks employment elsewhere (Devlieger, 1998). The context of the care provision should be carefully recorded and the roles of parents, grandparents, siblings, and the community should be given great importance (Saugestad, 1990).

Intervention and Responses

Institutional

Parents of children with disabilities and their children received assistance from various institutions. Special schools and integration units in their local areas featured prominently among these. Of the children with disabilities going to school, 38% are in integration provision, 6% are in total inclusion provision while 56% are in special schools. However it is important to note that many students with disabilities are not in school. Some are not in school because their school types are full (e.g. severe to profound multiple disabled children) or they have dropped out due to high fees and the harsh economic circumstances.

The clinics and local district hospitals are seeing many children with disabilities. The researchers visited Gokwe District Hospital and witnessed rehabilitation sessions of children with disabilities at the hospital. These were timetabled. The researchers were told that such sessions took place in most if not all district and provincial hospitals.

Most institutions were run by private voluntary organisations (e.g. churches, NGOs). There were a few government centres.

Community

Caregivers were asked if they knew of any programmes in their community that assisted them and gave them support in caring for their children with disabilities. Ninety-five percent of the caregivers did not know of the existence of any such programmes within their communities.

All the participants did not know of any intervention on disability championed by their local government authorities (both urban and rural councils).

When asked how their community could help support them in raising their children with disabilities, the care-givers gave the following suggestions:

- their children were hungry, and assistance in the provision of food was required.
- those in urban areas needed transport to carry their children with disabilities to and from school.
- they needed the community to be knowledgeable of the disabilities of their children.
- the care-givers wanted parents of disabled children within the same community to share information in support group meetings.

Asked how their local government could assist them, the care-givers gave the following answers:

- care-givers in urban areas wanted to be given employment so that they can earn a decent living for their disabled children.
- both caregivers from urban and rural areas talked of provision for their children in the form of free food and clothing
- they wanted the local authorities to build play centres for disabled children.

Support Groups

Some parents of mentally and physically handicapped children in urban areas knew and used the services of parental support groups. These groups met to share information and to learn skills that they could use at home. They also had play centres where children with disabilities spent part of the morning. Unfortunately, parents in the group discussions said the facilities were too few. The care-givers in the study did not know of support groups in

other disability areas. Also the support groups for parents of children with disabilities were not known in most rural areas visited by the researchers. These support groups were championed by an organisation of parents of handicapped children.

- Only five percent of the participants knew of any government policies or laws that protected the welfare of children with disabilities. The other 95% did not know of any such policies or laws. The 5% who said they were aware of the policies had little knowledge of the details.
- Again, only a small percentage (7%) of the participants knew of any programmes run by central government that directly assisted children with disabilities.

Asked how central government could support their children with disabilities, the following comments were made:

- Parents could not afford buying support devices and equipment that children with disabilities used such as wheelchairs, hearing aids, special boots, etc. They wanted government to buy these for the children.
- Most deaf children in schools and units for the deaf had hearing aids that belonged to the school and could not take them home. One parent said: "Its like leaving your ears at school when going home simply because one is poor."
- Care-givers wanted central government to make sure each disabled child had access to education and health by providing the facilities and making the services free to children with disabilities.
- Care-givers wanted their children to have post-secondary training programmes.
- Parents of children with multiple disabilities wanted schools for such children to be established. Most of these children are not in school.
- Care-givers wanted social welfare services to be available to every child with a disability. Children with disabilities are very expensive to manage and yet the majority of the care-givers are poor.
- In interviews with officials from institutions, it was mentioned that there was no budget for special needs education from Government revenue. The section was funded by donor organisations.

Emerging Gaps

Policy

- There are no clear policies and laws on the education of children and adolescents with disabilities in Zimbabwe. What is needed is for Zimbabwe as a country to have a Special Needs Education Act of Parliament. The Act will give children with disability a legal right to education, with government having certain obligations to fulfil.
- There are a few policies that Government departments use to provide services to children and adolescents with disabilities. Unfortunately, these policies are not made public. Hence, parents and other interested parties do not know them—once the child has been identified by the clinic or hospital as having a disability, there are no clear-cut policies on what happens next. Caregivers seemed to grope in the dark and shop around for assistance without guidance.
- There is a gap on the policy of financing disability evidenced by some key ministries with departments or sections on disability with inadequate allocation. Some areas that need financial assistance by Government and should be covered by clear policies are: support equipment and devices; education; health; food security; and shelter. Care-givers were worried about the post-secondary education and training of their children with disabilities.
- Absence of nationally representative data on people with disabilities in the country. The Central Statistics Office does not have statistics based on the National Census on how many people with disabilities are in the country.

Programmatic

- There are no specific programmes available to provide counselling services for children and adolescents with disability. Various efforts exist in terms of health, education and social welfare, but no counselling services are in place.
- Most children with severe to profound multiple disabilities are not in school. These children required more assistance and have more challenging issues and yet receive the least intervention.
- Negative attitudes, beliefs and stigmas against disability are prevalent in Zimbabwe. Yet, there are no deliberate programmes to educate the public on disability. This should be done beyond the awareness level. People need to be sensitised and made conscious about the issues involved in disability.

- Husbands and male care-givers featured prominently either as not being involved with their children with disabilities or as being negative to the entire situation. There are presently no programmes in place that work with this issue. It is an identified gap that needs to be addressed.
- Children with disabilities in boarding schools are dropping out because these schools are expensive. They are in those schools not out of choice but because there is no special needs education provision/facilities in their local schools. Some units for the blind and for the deaf have closed because of this problem. There is no programme that provides assistance to these children.
- The issue of poverty as a basic factor that triggered other problems ran throughout the research. Programmes that empower care-givers to generate independent financial resources to be able to care for their disabled children are extremely few.
- There are no significant community efforts at village or township level to support children with disabilities and their parents. Local authorities are not involved in the welfare.

Recommendations

Policy/Legal

- The current Disability Act is not comprehensive and is non-committal. There is need to re-do the Act so that it clearly spells out who is responsible for what, especially with respect to Government's responsibilities.
- The primary ministry responsible for people with disabilities is the Ministry of Public Service, Labour and Social Welfare. Already, there is mindset among policymakers that people with disabilities are welfare cases. There is need to integrate the needs of children with disabilities across ministries.
- Each ministry that has a department or section to with the issue of disability should have a clear budget for that section. This will demonstrate one form of Government's commitment.
- Specifically the Ministry of Education, Culture and Sport needs to come up with a Special Needs Education Act (Special Education Act). Such an Act should be comprehensive detailing who is responsible for what and who pays.

Programmatic

- Children are becoming disabled in some cases due to diseases that can be prevented (e.g. polio, measles, tuberculosis). There is need for the Ministry of Health to ensure all children are immunised and have access to health when they are sick. Sufficient funding should be allocated to immunisation programmes. Some of the money should be used to educate parents on the importance of immunisation. At the same time there are certain religious groups that do not believe in immunisation and education programmes should target such groups as well. There is need for village health workers and the local clinic to educate pregnant mothers on their own good nutrition and health. Poor health and nutrition by pregnant mothers is a high risk for the child to be born disabled.
- Children did not have support equipment and devices (wheelchairs and hearing aids) to use at home and in some situations to use after school. Some of the support equipment used in school was broken and not functioning. Government must find the needed money to buy this equipment for children with disabilities. Again, this is another situation where parents of children with disabilities and disabled people themselves need to be mobilised and empowered to be able to demand support services from government. Parents of children with disabilities and disabled people themselves need to form pressure groups that ensure that children with disabilities have the equipment they need to be mobile and lead as normal a life as possible.
- Many parents of children with disabilities do not know the laws, policies and regulations that assist their children. There is need that such laws, policies and regulations be printed in Shona and Ndebele. Parents need to be educated on such policies.
- Currently, several organisations have programmes in the field working with disability in one way or the other. However, there is no co-ordination of interventions, which may lead to either duplication or omission of important issues. In view of the above, there is need for an audit of the existing programmes by various voluntary service organisations to establish gaps in service provision for children with disabilities.
- Children with disabilities are dropping out of school because of lack of school fees. Chances are high that such children end up unemployed, beggars, street kids, and leading miserable lives. A short term solution would be to set up a bursary fund in the Ministry of Education, Sport and Culture to support these children. This should not be left only to the Department of Social Welfare because it is not a welfare issue but a right to education issue.

- There is need to mobilise parents of disabled children that they form support groups to help each other. In some disability areas, such groups exist and they need consolidation. Parents supporting each other in their communities would be ideal. It was noted that each district hospital has a rehabilitation technician and thus is further suggested that rehabilitation technicians be given the responsibility to start parent support groups in their districts. This is occurring in Gokwe where the rehabilitation technician at Gokwe Hospital was mobilising parents into support groups. This is a good model that could be replicated at each district hospital.
- Tied to the issue of support groups is the issue of skills. Some parents need skills on how to manage and care for their children with disabilities. Again, the district hospital rehabilitation technician is best placed to teach the parents the required skills.
- There is need for social mobilisation targeted at fathers. In the study, fathers featured badly as being negative to disability. Yet, fathers only came into the scene of the child with disabilities after the effect. It is recommended that Priests be encouraged to counsel partners on HIV/AIDS and the possibilities of giving birth to a child with disabilities prior to marriage. In most churches, partners attend marriage lessons conducted by the priest. It is during such sessions that the discussion and counselling can take place.
- A multi-prolonged approach to public awareness is required, empowering people with disabilities to be their own advocates. Public awareness campaigns are necessary as a continuous exercise. People with disabilities themselves can be at the forefront of these campaigns. Existing organisations of the disabled (e.g. National Council of Disabled Persons Zimbabwe) can run such a programme. Private companies should be encouraged to use people with disabilities as models to advertise their products and the mass media to show or report on cases of successful people with disabilities in society. Emphasising successful people creates a positive image of disability.
- Early intervention in children's lives contributes towards the development of a culture of positive attitudes towards disability. Intervention could begin at pre-school level. Sensitising the children on the issues of disability should be included in their curriculum together with other civic and human rights issues. Also, children with disabilities should learn together with non-disabled children in integrated settings right from pre-school. If children grow up playing together with disabled children, they are likely to accept them and treat them just like other ordinary children. Secondly, there is need to develop positive attitudes and positive knowledge about disability amongst personnel who provide services to communities. For instance, agricultural extension workers are based in the villages. They work with communal farmers on a day to day basis and address gatherings of these farmers frequently as part of their work. Agricultural extension workers could include disability issues when addressing such gatherings. They should also have the knowledge and skills to be able to help someone with a disability (e.g. a blind person) who wants to be a farmer. This will require the development of materials to train such personnel both at pre-service and at in-service levels.
- There is need for representation in government of people with disabilities by the people with disabilities themselves. In the last Parliament of Zimbabwe there was an individual who was disabled and represented people with disabilities in Government. Unfortunately it is no longer the case now. Unless people with disability have two or three people in Parliament standing for their rights many of the efforts expended in advancing the cause of disabled people will be lost.
- The Registrar General's Office should be required to include in the census form a section on disability so that whenever a National Census exercise is undertaken, the number of people with disabilities in the country is known.

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