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Marginalisation of the Marginalised: Plight of Children with Disabilities

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Abstract

This study sought to find out the different types of care given to children with disabilities (CwDs), 3-5 years and the capacity of parents in providing for their needs. Attitudes and perceptions of parents towards CwDs were also explored in the study. The study was conducted in the context of the United Nations (UN) Convention on the Rights of the Child (CRC) (1989) and the first Education for All (EFA) goal (UNESCO, 2007). Parents, teachers and district level administrators participated in the study. Five rural districts were selected. The study adopted both qualitative and quantitative approaches. Findings revealed that parents face challenges in providing for CwDs under their care. Challenges included stigma, myths attached to disability, coming to terms with having a child with a disability, and lack of resources. It was also noted that there were some appropriate care practices which parents were employing despite the limiting factors in the communities they existed. The conclusion of the study was that although parents strive to provide good care for their CwDs, they have limited capacity in terms of knowledge and resources. Consequently, they require professional assistance to enhance their knowledge and skills on basic care of such children, as well as environmental resources and referral services. It was also observed that there was need for financial and material support to enable parents to access both education and health services for their CwDs.

Background to the Study

Several research findings submit that the early years are critical in the child's lifelong development. Hepburn (2004) argues that it is the children's early experiences that set the stage for future development and success in later life. In this regard, the first EFA goal also explicitly calls for the expansion and improvement of Early Childhood Development (ECD) for the most vulnerable and marginalised children. The goal's focus on marginalised and vulnerable children is consistent with the UN Convention on the Rights on Children (1989) and the importance of equity and inclusion. As noted by the EFA Global Monitoring Report (2007), marginalisation and vulnerability are specific to certain difficult contexts such as armed conflict and poverty. Others relate to children's conditions like orphanhood, homelessness and disability, which constitute the thrust of this discussion.

In this study, marginalised communities are communities that are impoverished. The Disability Act of Zimbabwe (revised 1996) defines 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” (p51). Children with disabilities covered in this study include those tabulated below.

Table 1: Types of disability and description

Form of disability	Description
Physically impairment	Includes upper limb(s) disability, lower limb(s) disability, manual dexterity, and disability in co-ordination with different organs of the body. Often cause a person to use special equipment like a wheelchair, cane, or prosthetic limb. Persons with physical disabilities may have difficulty with movement or self-care (http://www.disabled-world.com/disability/types/ and http://academic.cuesta.edu/acasupp/DSPS/IDISABIL.HTM)
Visual impairment	This includes blindness and ocular trauma. Some of the vision impairments include scratched cornea, scratches on the sclera, diabetes-related eye conditions, dry eyes and corneal graft (http://www.disabled-world.com/disability/types/).
Hearing impairment	Includes people who are completely or partially deaf. People who are partially deaf can often use hearing aids to assist their hearing. Deafness can be evident at birth, or occur later in life from several biological causes. For example Meningitis can damage the auditory nerve or the cochlea. Deaf people use sign language as a means of communication (http://www.barrierbreak.com/typesofdisabilities.php)
Mental impairment	Includes mental retardation, speech disorders and general learning difficulties such as down syndrome. Mentally impaired people have difficulty learning, remembering and communicating information (http://www.barrierbreak.com/typesofdisabilities.php).
Albinism	An inherited condition that is present at birth. It is characterized by lack of the usual amount of pigment melanin, which is the substance that gives colour to the skin, hair and eyes. Albinism always affects vision and may ultimately lead to skin cancer. The genes that cause albinism also cause abnormal development of the nerve connections between the eyes and the brain. Most people with albinism are

Form of disability	Description
	<p>born to parents without the condition, but both parents must carry a copy of the defective gene and both must pass on that copy to their child</p> <p>(http://www.healthofchildren.com/A/Albinism.html and http://www.answers.com/topic/albinism).</p>
Acquired Brain Impairment	<p>A verified deficit in brain functioning which results in total or partial loss of cognitive, communicative, motor, psychosocial, and/or sensory perceptual abilities</p> <p>(http://www.disabled-world.com/disability/types/).</p>
Invisible/heath-related disability	<p>A medical condition which includes sicknesses or diseases such as epilepsy, diabetes, and cancer. Another invisible disability is psychiatric disability characterized by disorders of mood or feeling states either short or long term. This category includes conditions like bipolar disorder and depression among others</p> <p>(http://www.disabled-world.com/disability/types/ and http://academic.cuesta.edu/acasupp/DSPS/IDISABIL.HTM)</p>
Spinal Cord Disability	<p>it can be a birth defect or spinal cord injury which can lead to lifelong disabilities. Normally injury occurs due to severe accidents. In an incomplete injury, the message conveyed by the spinal cord is not completely lost. Whereas a complete injury results in a total dis-functioning of the sensory organs</p> <p>((http://www.disabled-world.com/disability/types/).</p>
Elderly Disability	<p>With age, every human being acquires some sort of disabilities including memory loss, hard-of-hearing, deteriorating vision, and difficulty in climbing stairs among others http://www.barrierbreak.com/typesofdisabilities.php).</p>

Throughout this article, the terms 'parents' and 'caregivers' are used interchangeably. These are individuals with substantial and ongoing involvement in the basic care, protection, guidance and general welfare of the child. This includes anyone who functions in the role of a family member like parents, older siblings, aunts, uncles, grandparents, cousins, and foster or adoptive parents. These are the people who spend most of the time with the child, and have the most direct influence on the child's learning and development: Second, the parents play a central role in providing for many of the child's needs. Likewise studying parents' provision of care of CwDs is legitimate for one who wants to understand the development of CwDs. The mental, physical and socio-emotional handicap(s) of CwDs, and their being raised in a marginalised community (poverty-stricken area) lends them the description: the marginalised of the marginalised.

The United Nations General Assembly (UNIGASS) adopted the CRC on 20 November 1989. The convention spells out the complete range of international human rights on children. The guiding principle of the Convention includes non-discrimination; adherence to the best interests of the child; the right to life, survival and development; and the right of the child to participate in all social activities and services provided in his/her country. The Convention sets out ten principles to guide the protection of the child. Of immediate interest to this discussion is Principle 7 (Seven), which states that,

The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education, which will promote his general culture, and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgment, and his sense of moral and social responsibility, and to become a useful member of society. The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with his parents. The child shall have full opportunity for play and recreation, which should be directed to the same purposes, as education; society and the public authorities, shall endeavour to promote the enjoyment of this right.

Consistent with Principle 7, in Zimbabwe rural communities where this study was carried out, the bulk of the care for CwDs takes place in the home environment. Those responsible for the care of these children include members of the family or household. Pestalozzi in Crain (1991) supports this when he states that parents are the first teachers of their children. However, the care in question is not the responsibility of the parents alone. It is extended to neighbours and the larger community, in this case the village and public authorities. Public authorities comprise rural district council, DA's office, and ministries of social welfare, education, and health, traditional leaders such as the chief or headman and finally the state itself.

The Zimbabwe's National Disability Survey (ZNDS) (1981) reported that 52.4% of people with disabilities in Zimbabwe have never attended school, 16.5% have attended school for up to two years, and 28.2% have not gone beyond grade seven levels. According to the Central Statistical Office (1997) the total number of people with disabilities was estimated to be about 2% of the total population of Zimbabwe. In the study, 57 232 children with disabilities (0-19 years) were identified in the country. Of these, 79% were from rural areas while 21% were from urban areas. Since then, no other survey on disability has been conducted. In addition, Nyandiya-Bundy et al (2002) submit that there are

many children with disabilities who remain invisible to national surveys as well as the education and health services due to tendency to hide disability among certain cultures. The Zimbabwe National Disability Survey (ZNDS) of 1981 estimated that about 41% of disabilities occur in the first four years of life, during which period they are not always easy to detect. The CEDC Report (1998) points out that definitional issues and terminologies add to the complexity. Consequently, accurate information on the incidence and prevalence of different disabilities among children in Zimbabwe is not readily available. Nyandiya-Bandy et al (2002) state that the Central Statistical Office (CSO) age bands of 0-4 years and 5-9 years make estimates of pre-school aged children with disabilities virtually impossible, considering the fact that in Zimbabwe children enroll for preschool education at 3 years and complete at 5 years. This lack of information on CwDs makes this study important.

Furthermore, it is of paramount importance to note that CwDs, by reason of their physical, mental and/or socio-emotional handicap(s), face challenges that ordinary children do not experience. As a result, they require special safeguards and care to realize their full potential. CwDs will always be adults at some point and thus should be fully prepared to live an independent life in society. In this regard, it is imperative to consider that this is dependent on the foundation laid during the formative years whereby the major players in influencing early learning and development are the parents/caregivers. Consequently, studying the care of CwDs and the capacity of parents/caregivers in providing care is important to establish what is obtaining currently and enable informed intervention where necessary. Intervention will help CwDs acquire knowledge, skills, values and attitudes that will enable them to be useful members of the society.

Research Questions

The study was based on the following research questions:

1. What is the prevalence of children with disabilities in the marginalised communities?
2. Are parents knowledgeable in providing for the needs of children with disabilities?
3. Do the parents have capacity in providing for the needs of children with disabilities?
4. What are the parents' attitudes and perceptions towards children with disabilities?

Methodology

This study employed both the quantitative and qualitative approaches. The quantitative approach was in the form of questionnaires which were closed-ended. These questionnaires were for parents, teachers and administrators. Parents included biological parents, grandparents, kinsmen and non-relatives who provided care to children with disabilities. Teachers included the school head, teacher-in-charge (TIC) and ECD teachers. These complement parental care for children with disabilities that are enrolled at the ECD centres and those that participate in their community outreach programmes. Administrators were district administrators, education officers, nursing officers, welfare officers, and ECD trainers. These singly or in collaboration, provide support services to families with CwDs. It should be noted that chiefs and headmen were covered under the questionnaires for parents. Questionnaires provided information to determine how many of the participants held what perceptions.

To complement, data collected through the questionnaire, the qualitative approach was used. The qualitative approach focuses on the process of social interaction and is holistic in that it attempts to provide conceptual basis for understanding complex issues (Cohen and Manion, 1994). In this case, the focus is on attitudes and perceptions of caregivers towards CwDs. This approach seeks insights rather than statistical analysis (Chisaka, 2001). Hence interviews were carried out with administrators and teachers as follow up to questionnaires. Focus group discussions (FDGs) were conducted with parents to probe on information collected through the questionnaire. Different sources and instruments for collection of data enabled triangulation. Triangulation is based on the argument that the best way to be sure that the data collected provides the researcher with a valid picture of what is being measured are to cross-check data with that collected through another source or method. By focusing on the need to validate results and cross-check information from alternative sources with information collected through different methods, the researcher was assured that the results obtained are valid, in this case attitudes and perceptions of caregivers towards CwDs.

Location of the study

The study took place in Hwange, Bulilima, Mangwe, Zaka and Binga rural districts representing rural Zimbabwe. The rural population survives on subsistence agriculture and the majority of the rural populace are not or have never been formally employed (UNICEF, 1998). Kuyayama and Chivore (2009) point to the problem of accessing health services, hygiene services,

protected water and nutrition. Consequently, rural Zimbabwe falls into the category of marginalised communities.

The Sample

Participants of the study included 200 parents (100 biological parents, 2 chiefs, 3 headmen, 95 kinsmen which included grandparents, aunts and uncles among others), 200 teachers (50 primary school heads, 5 ECD district trainers, 100 ECD class practitioners and 45 teachers-in-charge) and 20 administrators (5 district education officers, 5 district administrators, 5 district nursing officers, and 5 district social welfare officers). The sample is representative as it reflects the characteristics of the target population. All participants were from rural communities and are directly or indirectly involved in the care of CwDs. Because they are all part and parcel of the Zimbabwe rural community, their experiences in caring for CwDs are considerably similar. The five districts represent 14% of the target population. As a result, findings can be generalized to the target population.

Purposive sampling was employed to come up with the sample. The researcher targeted people who were knowledgeable of the required information. All parents/caregivers and teachers had practical experiences with 3-5 year old children with disabilities under their care. The administrators were directly involved in programmes for the care of all children under five and orphans and vulnerable children, of which children with disabilities are part and parcel.

Data Analysis

Both quantitative and qualitative methods were used to analyze data. Data collected through questionnaires were organised into categories and quantified into percentages and presented in bar graphs. A qualitative analysis of statements and comments made during interviews and FDGs was made. Analysis of qualitative data was done at two levels. The level first involved the coding and extraction of trends from interviews and FDGs. The second level involved the categorization of noted trends and giving meaning to the information.

Procedure

A pilot study was carried out to assess methodology which involved, testing the data gathering instruments, assessing logistics, approaches, needs, establishing trends and adjust them accordingly. The pilot study was conducted in Seke rural district at 3 ECD centres and the communities in which they were located as well as the government district offices. The government district offices included the District Administrator (DA), District Social Welfare Officer (DSWO), District

Nursing Officer (DNO) and District Education Officer (DEO). Data were collected over 4 days. The results of the pilot revealed that mental, physical, visual and hearing impairments as well as albinism were the most common types of disabilities. Interviews with parents proved to be time consuming as they came in large numbers. As a result FDGs were employed. Like ECD teachers and administrators, parents could read and write but they were not proficient with the English language. As a result FDGs with parents were conducted in the first language. Collection of data for the main study was done over 5 weeks. Each district had an allocation of 7 days. Results were then analyzed and conclusions drawn accordingly.

Data Presentation and Discussion

The study explored care of children with disabilities and the capacity of their caregivers in providing for their needs in Zimbabwean marginalised communities. Focus was on types of disabilities and their prevalence, knowledge and capacity of caregivers in providing for the needs of CwDs, and caregivers' attitudes and perceptions towards disability. Figures 1 to 2 and Tables 1-5.2 show frequencies and trends of participants' views respectively. Data were presented as per research question and common trends were presented.

Research Question 1: What is the prevalence of children with disabilities in the marginalized communities?

Table 1: Types and Prevalence of Disabilities among Children

Types of disability	Parents						Teachers					
	Not Prevalent		Prevalent		Total		Not Prevalent		Prevalent		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Mental Impairment	52	26	148	74	20 0	10 0	39	19.5	16 1	80.5	20 0	10 0
Physical Impairment	44	22	156	78	20 0	10 0	33	16.5	16 7	83.5	20 0	10 0
Visual Impairment	37	18.5	163	81.5	20 0	10 0	31	15.5	16 9	84.5	20 0	10 0
Hearing Impairment	29	14.5	171	85.5	20 0	10 0	29	14.5	17 1	85.5	20 0	10 0
Albinism	25	12.5	175	87.5	20 0	10 0	14	7	18 6	96	20 0	10 0
Acquired Brain Impairment	190	95	10	5	20 0	10 0	17 8	89	22	11	20 0	10 0
Invisible/health-related disability	164	82	36	18	20 0	10 0	17 1	85.5	29	14.5	20 0	10 0
Spinal Cord Disability	192	96	8	4	20 0	10 0	18 0	90	20	10	20 0	10 0
Elderly Disability	200	100	-	-	20 0	10 0	20 0	100	-	-	20 0	10 0

er (DEO). Data were that mental, physical, ere the most common be time consuming as employed. Like ECD rite but they were not Gs with parents were e main study was done ys. Results were then

d the capacity of their abwean marginalised nd their prevalence, e needs of CwDs, and y. Figures 1 to 2 and ts' views respectively. common trends were

with disabilities in the

children

t	Teachers		Total	
	N	%	N	%
5	16	80.5	20	10
	1		0	0
5	16	83.5	20	10
	7		0	0
5	16	84.5	20	10
	9		0	0
5	17	85.5	20	10
	1		0	0
	18	96	20	10
	6		0	0
	22	11	20	10
			0	0
5	29	14.5	20	10
			0	0
	20	10	20	10
			0	0
			20	10
			0	0

Table 2: Recurring Responses on Types and Prevalence of Disability

Response A	There are two children at this centre who are physically impaired. One has a spinal bifida and the other is lame - he must have suffered from polio. They are the only ones here. In the village there is only an albino and she is not attending preschool.
Response B	I have a blind child at home, 5 years old. She is the only blind child in this community. I hear of three physically impaired 4 year olds in this village and two albinos from the same family in the neighbourhood. I don't know of any other. Its very few of us parents with this challenge of CwDs.
Response C	Blind 3 -6 year olds not at all. Perhaps we don't see them because they cannot play with the others by virtue of their condition. There is a crippled child cared for by his grandmother and a hard of hearing orphan staying at the church. I have not seen or heard of any other disabilities in the village, even in the neighbourhood.
Response D	My child is a d own syndrome. In this village I am the only one with a disabled child. At the preschool there are no such children. May be its because they do not enrol children like mine because she poses many challenges in terms of care.

To answer this question, parents/caregivers and teachers were requested to indicate types of and prevalence of CwDs found or common in their communities among children, 3-5 years [Ref: Table 1 and Table 2]. Out of a total of 200 parents 148 (74%), 156 (78%), 163 (81%), 171 (85.5%) and 175 (87.5) said cases of mentally impaired, physically impaired, visual impaired, hearing impaired and albinism respectively, were prevalent. Out of 200 teachers 161 (80.5%), 167 (83.3%), 169 (84.5%), 171 (85.5%) and 186 (96%) submitted that cases of mentally impaired, physically impaired, visually impaired, hearing impaired and albinism respectively, were prevalent. These results suggest that for both categories of respondents, CwDs are in various forms and the most common are mental, physical, visual, hearing impairment and albinism. The other forms of disability with scores less than 50% [Ref: Table 1] and not mentioned in Table 2 [Ref: Responses A-D] were acquired brain impairment, invisible/health-related disability, spinal cord disability and elderly disability. Not mentioning these disabilities may mean that they are not prevalent. Furthermore, results show that disabilities were in a minority [Ref: Fig 1 and Table 2: Responses A-D]. ECD centres enroll up to an average of 90-120 children and having 2 CwDs out 90 or 120 [Ref: Table 2-Response A] and none at all [Ref: Table 2-Response D] can be evidence that 3-5 year old CwDs are in a minority. Though in a minority, the fact remains that disabilities exist.

Research Question 2: Are parents/caregivers knowledgeable in providing for the needs of children with disabilities?

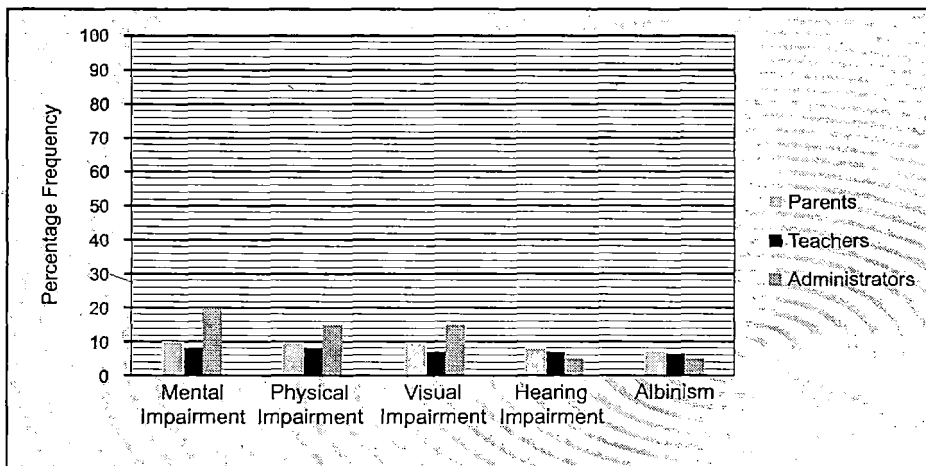


Fig 1: Parental knowledge in providing needs of CwDs

Table 3: Recurring Responses on Parental Knowledge in Providing Needs of CwDs

Responses of participants	Contemporary Views
A: We want to implement what is recommended by the experts, but we lack the resources. So we rely on our traditional practices.	The Inter -Censal Demographic Survey (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 tuberculosis. 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. Pregnant mothers infected by HIV/AIDS and are constantly ill and at risk of giving birth to children with disabilities (http://www.unicef.org/french/evaldatabase/files/ZIM). Disability is a reduction, restriction or disadvantage that
B: Having a CwDs is a curse from God or the ancestral spirits and you have to repent to God or appease the ancestors respectively	
C: Having a CwDs is a misfortune: a bad spell or a result of witchcraft	
D: One must visit the faith healer or the village herbalist to seek treatment for C wDs	
E: One has to pray to God. One day He will hear the plight of your CwDs	
F: Was raised in a family without a CwD and I have no idea of how I should care for my CwD. As you know, we raise our children the way we have been raised	

Responses of participants	Contemporary Views
<p>G: Friends and neighbours assist but they also gossip about my CwD. They spy on my child in the name of assisting me. They say I am being punished by God and my ancestors. So CwD are stigmatised.</p>	<p>comes as a result of the impairment. This is compounded by society's expectations and the person's struggle to fit in. This shows how disability is a result of the gap that exists between a person's capabilities and society's demands. In light of this, society is what disables an individual, thus the need for society to adjust to suit the individual, rather than the individual adjusting to society demands</p>
<p>H: My CwD may need friends but he cannot play with them because of his condition. Look (pointing at the child) he cannot move or talk.</p>	<p>(http://www.newvision.co.ug/O/8/459/711453).</p>
<p>I: Sending my CwD to the school is transferring my own problems to strangers. I cannot do that. I will see to my own problems. God will never live me alone.</p>	

It was necessary to find out parental knowledge in providing for the needs of CwDs, 3-5years. Fig 1 and Table 3 above provide the responses of parents, teachers and administrators. Out of 200 parents, only 20 (10%), 19 (9.5%), 19 (9.5%), 16 (8%), and 15 (7.5%) said that they had knowledge to care for the mentally impaired, physically impaired, visually impaired, hearing impaired and albinos respectively. Out of 200 teachers 16 (8%) submitted that they were comfortable caring for the mentally impaired children. As for the physically impaired, visually impaired, hearing impaired and albinos; only 16 (8%), 14 (7%), 14 (7%) and 13 (6%) teachers said they were comfortable caring for CwDs. Out of 20 administrators (100%) only 4 (20%), 3 (14.5%), 3 (14.5%), 1 (5%), and 1 (5%) said that parents had knowledge to care for the mentally impaired, physically impaired, visually impaired, hearing impaired and albinos respectively. The results suggest that parents had limited knowledge of care of CwDs as indicated by the low scores submitted. They barely reached 50% [Ref: Fig 1] and parents beliefs and child care practices [Ref: Table 3-Reponse A-I].

Table 3-Responses B, C, D, E and G suggest that parents associate disability with witchcraft, misfortune, and/or anger of the ancestral spirits or God. There is also evidence of parents searching for cure from herbalists and faith healers, with the hope of eliminating the disability. Responses A, F, H and I show that parents lack skills to care for CwDs. There are also indications of associating disability with helplessness or inability [Responses H and I]. Response G and I show bitterness, depression, resentment and despair which result in abuse of the child by isolating

him/her and not sending him/her to school respectively. Elements of stigmatization evident in Response G also suggest lack of knowledge about care for CwDs among the 'perpetrators', who are part of the caregivers in the village. Parents' beliefs about disability and the ways in which they react to disability are contrary to the professional or contemporary explanations. Overall, therefore, to the question that sought parental knowledge about providing the needs of CwDs, participants' views suggested that their knowledge was limited.

Research Question 3: Do parents have capacity in providing for the needs of children with disabilities?

To answer the question, Figure 2 and Table 4 contain data on the parents' capacity or means to look after or provide for the needs of CwDs.

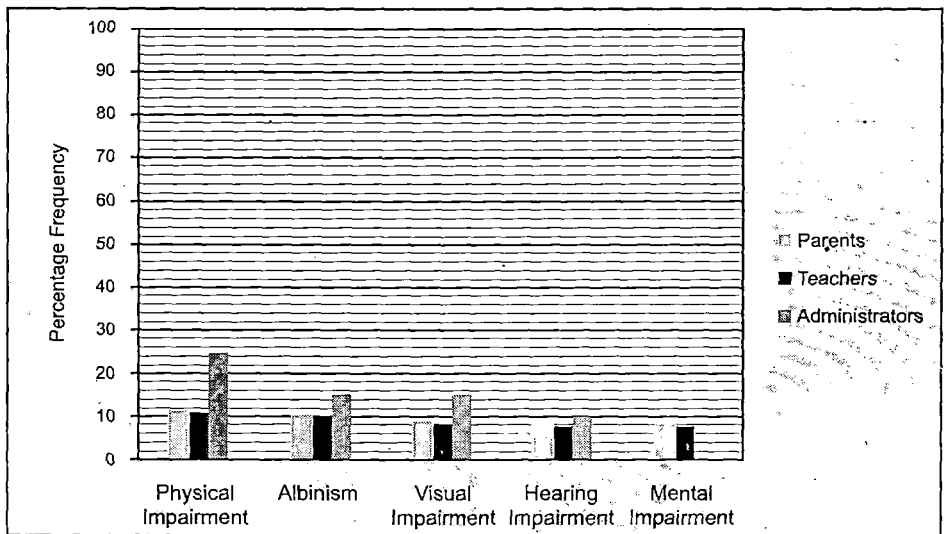


Fig 2: Parental capacity in providing needs of disabled children

Table 4: Recurring Responses on Parental Capacity in Providing Needs of CwD

Response A	I am a poor person. I cannot buy a wheelchair. Look at my miserable house. I have no cattle, not even a chick. Where do I get the money to pay for the hospital fees?
Response B	They (parents) do not have money for the fees required at the special schools. It's very serious because they even struggle to pay fees for children in the normal stream.
Response C	Government and Non -Governmental organizations often give us food, clothing and social support, but that does not take away the disability from my child.
Response D	I did not complete school. I cannot use sign language nor have knowledge of where I can be assisted. The teachers and the environmental health workers in the village could not assist me.
Response E	Albinos are enrolled in the normal stream but parents lack finance to buy lotions, shoes, glasses and hats for these children.

Fig 2 reflects the percentage frequencies of views of parents, teachers and administrators on capacity of parents in providing the needs of children with disabilities. Out of 200 parents 23 (11.5%), 21 (10.5%), 18 (9%), 17 (8.5%) and 17 (8.5%) said they had capacity to care for children physically impaired, albinos, visually impaired, hearing impaired and mentally impaired respectively. Out of 200 teachers 22 (11%), 20 (10%), 17(8.5%), 17(8.5%) and 17 (8.5%) submitted that parents had capacity to care for the physically impaired, albinos, visually impaired, hearing impaired and mentally impaired respectively. Out of 20 administrators 5 (25%), 3 (15%), 3 (15%), 2 (10%), and 0 (0%) said that parents had capacity to provide the needs of children physically impaired, albinos, visual impairment, hearing impaired and mentally impaired respectively. Though capacity seems limited, administrators were of the view that parents would handle the albinos and physically and visually impaired children better. Administrators may have noted this during interactions with parents and their CwDs during outreach support programmes. Overall, results show that the capacity of parents was negligible since none of the participants' scores went up to 50% (Ref: Fig 2).

Recurring participants' responses during interviews and FDGs suggest limited capacity of parents due to poverty [Ref: Table 4]. Parents are limited economically to provide decent clothing, meals and shelter to CwDs. They could also not pay for the education and health services for their CwDs [Ref: Table 4-Response A, B and C]. It was also submitted that some parents were not aware of

referral services available [Ref: Table 4-Response D]. Though they lacked capacity, some parents were not concerned about realizing the learning and developmental needs of their child; they were preoccupied with getting treatment so that the disability is eliminated [Ref: Table 4-Response C]. Overall, therefore, findings indicate that parents' capacity in providing for the needs of children with disabilities were that capacity of parents is limited.

Research Question 4: What are the parents' attitudes and perceptions towards disability?

Table 5.1: Parental attitudes and perceptions towards disability

Activities/interactions	Do not allow		Allow	
	N	%	N	%
Play	22	11	184	89
Study	15	9	190	91
Eat	30	15	170	75
Bath	75	38	136	62
Share bedding	72	36	168	64
Share facilities	24	12	176	88
Share eating utensils	78	39	122	61
Share clothing	60	30	156	70

Table 5.2: Recurring Responses on Parental Attitudes and Perceptions towards Disability

Response A	I allow my able-bodied children to interact with CwD but there must be an adult to keep an eye, because the CwD can be hurt.
Response B	I do not allow my children because it can be dangerous. I fear that my child may get the disability.
Response C	Anybody can be disabled. ' <i>Seka urema wafa</i> ' (We do not know our destinies. You cannot discriminate).
Response D	Children are at times scared of their peers with disabilities because they do not understand. We encourage them, but they are far too young to understand.
Response E	Some parents do not keep these children (CwD) smart. It's therefore difficult because young children can be exposed to unhygienic conditions which are a health hazard.
Response F	Normally they (parents) allow them because it's not by choice that one has a disability. It's just a misfortune. However, it depends on the severity of the disability. Other children, even adults, are not comfortable to interact with CwD.

Response G	We allow our children to interact with children with disabilities but we never feel pity for those children (CwD) and we never give us anything we cannot do.
Response H	I have not witnessed any of my children interacting with children with disabilities when they look at my child and say 'that child is disabled' they do not interact with mine it's not possible. They neither move nor talk. It depresses me. I have seen children of his age playing... (Parental sob).

Information regarding parents' attitudes towards children with disabilities is contained in Table 5.1. The aim was to try and establish whether parents allow their able-bodied children to interact with their peers with disabilities. In this section because they are the primary caregivers, they have direct control of their interactions with their children. Table 5.1: out of 200 parents, 184 (89%), 176 (88%), 122 (61%) and 156 (70%) allowed their able-bodied children to play, study, eat, bathe, share eating utensils and share clothing, respectively. These results suggest that the majority of parents allow themselves, allow their able-bodied 3-5 year old children to interact with disabled peers. However, though scores for play were 89%, 88%, 61% and 70%, scores noted for bathing; sharing eating utensils and share clothing, respectively, were 62%, 64%, 61% and 70%. These results suggest that some parents seem uncomfortable allowing their children to interact with their impaired peers. Explicitly, there are some indications of discomfort from parents.

In view of data in Table 5.2, parents' attitudes are influenced by cultural and traditional beliefs (see Table 5.2 -Response A, B, C, and F). The results suggest that parents allow their able-bodied children to interact with children with disabilities. The fact that they cannot predict their destinies and that the situation with the CwDs may be beyond their control, parents, allowing their children or not to interact with children with disabilities [Ref: Table 5.2.-Responses F and G]. It is inevitable but parents would hide behind

Response G	We allow our children to interact with CwDs when the disability is not severe. We feel pity for those children (CwDs). However God has a purpose in this life. He will never give us anything we cannot handle.
Response H	I have not witnessed any of my neighbours discriminating my child but I do not like it when they look at my child and say "Shame". Even if they wanted their children to interact with mine its not possible because my child has a complex condition. He can neither move nor talk. It depresses me. Its very painful to me when I see other children of his age playing... (Parent terminates interaction and breakdowns into a sob).

Information regarding parents' attitudes and perceptions towards 3-5 year old children with disabilities is contained in Tables 5.1 and 5.2 respectively. The aim was to try and establish whether parents would let their able-bodied 3-5 year old children interact with their peers with disabilities. Only parents participated in this section because they are the primary caregivers of children, 3-5 years and have direct control of their interactions with the immediate environment. As per Table 5.1: out of 200 parents, 184 (89%), 190 (91%), 170 (75%), 136 (62%), 168 (64%), 176 (88%), 122 (61%) and 156 (70%) said that they allow their able-bodied children to play, study, eat, bath, share bedding, share facilities, share eating utensils and share clothing, respectively with their impaired counterparts. These results suggest that the majority of parents, as given by parents themselves, allow their able bodied 3-5 year old children to interact with their disabled peers. However, though scores for the negative view did not go up to 50%, scores noted for bathing; sharing bedding and eating utensils with CwDs suggest that some parents seem uncomfortable allowing their able-bodied children to interact with their impaired peers in such circumstances. Though not explicit, there are some indications of discrimination against CwDs among a few parents.

In view of data in Table 5.2, parents' attitudes and perceptions seemed to be influenced by cultural and traditional beliefs, values and practices [Ref: Table 5.2 -Response A, B, C, and F]. The responses indicate that parents allow their able-bodied children to interact with CwD because of fear of the unknown. The fact that they cannot predict their destiny, they seem not to discriminate because the situation with the CwDs may befall their families. In the case of other parents, allowing their children or not depend on the severity of the disability [Ref: Table 5.2.-Responses F and G]. It seemed elements of discrimination were inevitable but parents would hide behind the issue of lack of skills to interact

with CwD and failure of some parents to keep the CwD smart [Ref: Response F and E]. The challenge of coming to terms with disability as a permanent condition for their children seems to create feelings of bitterness, distress and despair among parents [Ref: Table 5.2-Response H]. Furthermore, the "shame" in Response H gives an indication that CwDs are viewed as 'objects of pity'. However, despite the challenges parents encounter in caring for CwDs, they seem to be determined to soldier on with the hope of God's intervention at some point [Ref: Table 5.2-Response G].

Overall, therefore, to the question on parents' attitudes and perceptions towards disability, the study found that there were elements of discrimination which were however, attributed to lack of skills to interact with CwDs between parents and able-bodied children. In cases where there was no discrimination, the type of disability was not severe and/or that it was not culturally acceptable to discriminate against disability, particularly, in public. Furthermore, sympathy for CwDs found some parents allowing their able-bodied children to interact with their impaired counterparts. Data from interviews and FDGs may explain why there could be scepticism on the genuineness of questionnaire data which revealed that there was no discrimination against disability. With regards questionnaire data, participants may have submitted socially acceptable responses.

Discussion

The results of the study are discussed under the following sub-headings: Types and prevalence of disability, parental knowledge in providing needs of CwDs, parental capacity in providing needs of CwDs and parental attitudes and perceptions towards children with disabilities.

Forms and Prevalence of Disability

The results show that five types of disability were prevalent in the disadvantaged communities of Zimbabwe. These were: physical, visual, hearing, mental impairments and albinism. These were not the only forms of disability but the most common. The other disabilities noted as not common among 3-5 year old children were acquired brain impairment, invisible/health-related disability, spinal cord disability and elderly disability. In addition, 3-5 year old CwDs were in a minority. This is consistent with the ICDS (1997) which estimated the total number of people with disabilities to be about 2%. However, the finding that there is tendency in Zimbabwe to hide disability as a result of stigmatization, makes it imperative to carry out a survey to establish the magnitude of this challenge. Censuses have not been able to solicit this type of data. The issue is

critical because disabled people are the marginalised of the marginalised-disadvantaged by virtue of their condition, and existing in contexts that are poverty-stricken. The rights of the able-bodied children do not supersede those of their counterparts with disabilities. The researcher raises this concern because in terms of ECD education priority, it was established that parents with CwDs prefer sending their able-bodied children to school compared to those with disabilities. To achieve the first EFA goal as per stipulations in the EFA Global Monitoring Report (2007), it is imperative that prevalence of CwDs be established to facilitate informed intervention.

Parental Knowledge in Providing for the Needs of CwDs

According to the results, participants indicated that parents strove to provide for their children but lacked the knowledge. Care for CwDs depends on knowledge parents have in terms of providing needs of these children (<http://www.articlesbase.com/childhood-education-articles/school-and-home-connections-880710.htm/>). The study found that caregivers did not seek professional help. Instead, parents sought assistance from faith healers and herbalists who focus, quite often, on causes of disability rather than solutions thereto. There was generally hope that the condition of CwDs could be corrected when children were still in their formative years, and this signifies lack of knowledge. Consequently, in such cases, parents may be carried away with the desire and belief in the possibility for cure rather than the learning and developmental needs of the child. It appears parents rarely considered the fact that CwDs would be adults at some point and they, as parents would not live forever to continue to provide for their children. There was likelihood that key developmental needs of children such as play (Froebel in Crain, 1991; classical and psychoanalytic theories of play in Strome, 1991) and acquisition of self help and life skills (Montessori in Morrison (1995) among others, may be considered trivial due to the preoccupation of seeking treatment. Consequently disabled children become more marginalised, existing in an already marginalised community.

Stern (1977) emphasizes the need for caregivers to read accurately and respond appropriately to the child's signals. Failure to do so would result in a mismatch of the child's cues and the caregiver's response which, Stern (1985) refers to as a 'misdance'. This, according to Stern, would result in disorganization in the child. It is, therefore, imperative that parents have a fair understanding of the challenges CwDs encounter by virtue of their condition and signals they use to communicate needs. For example, poor muscle tone in children with cerebral palsy may present a challenge to caregivers at feeding times. The involuntary

movements of the tongue maybe misinterpreted as lack of desire to eat by parents and, they may terminate the feeding. This may frustrate the child and undermine the child's sense of security which develops through trust that the caregiver is reliable and dependable (Erikson in Slavin, 2006).

Furthermore, lack of limited knowledge on disabilities has consequences on decisions parents take as strategies for intervention. The study found that parents were entangled by their cultural and traditional values, beliefs and practices which, on one hand, may foster and, on the other, undermine the child's learning and development. Disability was associated with misfortune/a bad spell, witchcraft, non-appeasement of ancestors and non-conformity to God's commands. Such beliefs are detrimental to child development since some parents turned away from professional service providers because they believed their assistance did not eliminate the disability. Based on the notion that development of children physically, intellectually, socially and emotionally, depends on the amount and quality of interaction with the caregiver, the belief that one should not discriminate against disability (*Seka urema wafa*) -was positive in that at least in public and/or by coincidence, CwDs would get opportunities to interact with community members.

As this study was carried out in rural Zimbabwe where there is communal ownership of children (Gelfand, 1973 and Mwamwenda, 1995), and where people are scared of discriminating against CwDs at least in public, CwDs may have vast opportunities for interaction with caregivers. Caregivers referred to here are adult family members, neighbours and other elders in the community. This means that CwDs' interactions; for example: playing with, talking with, and singing with among others; critical for the children in the formative years maybe readily available. In such situations, the assertion that relationships are the contexts of development (Mahler in Mahler, Pine and Bergman, 1975 and Stern, 1985) is therefore, realised.

Parental Capacity/means in providing Needs of CwDs

Parental capacity and means to look after disabled 3-6 year old children is based on the socio-economic status of parents. As noted, the five districts where the study was undertaken are economically and socially marginalised. Parents are relatively poor in terms of material and financial resources, as well as education; that is, academically and professionally. Due to such circumstances, they partly rely on assistance from the Government, NGOs, charity organizations and individual well-wishers in terms of food, clothing, and socio-emotional support for their CwDs. However, such support services are not

the impression that parents' attitude towards disability has to be seen by the public as positive, though in actual fact, parents do discriminate privately. Discrimination is a result of the myths and cultural beliefs that disability is a punishment from God or the ancestral spirits, and, as a result, nobody would want to be associated with sinners or victims of angered ancestors. People would want to portray a holy or "clean" image to the society as much as possible, hence the stigmatisation of CwDs.

As per the study findings, it was also noted that part of the discrimination tendencies among parents, were a result of lack of knowledge on the source of disability and professional guidance on care of CwDs. Participants expressed that people with knowledge/ experience of raising CwDs are in a minority as disabilities are not common. Consequently, assistance on how to care for CwDs was hard to come by. Fear of the unknown (of what happens when one plays, eats and shares bedding with CwDs among others), bred discrimination against children with disabilities, thus marginalising them. However, the UN Children Rights (1989): Article 3 states that a disabled child has the right to special care, education and training to help him/her enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and social integration possible. If parents were knowledgeable on the source of disability and general care of CwDs, may be discrimination tendencies would not have been there.

Besides providing knowledge on the circumstances that bring about disability and the general care of CwDs, focus on poverty reduction is critical to consider in a bid to lessen the plight of CwDs. Current literature suggests that when organizations deal with poor families, they are preoccupied with providing parenting skills without complementing this with capacity building to minimize poverty (<http://www.ericdigests.org/1996-1/face.htm> and <http://education.yahoo.com/reference/dictionary/entry/poverty>). The premise here is that poverty is stressful to most families who are already stressed with challenges of raising children with disabilities. This stress is passed on to the CwDs in form of what appears to be general neglect of that child. Parents may give up all efforts to assist the CwDs because they cannot access, for example, materials to promote healthy and hygienic environments and resultantly, they just give up. This type of attitude on the parent is unhealthy for a child who is already disadvantaged by his/her condition.

The study also found that CwDs were 'objects of pity' which may have resulted in disability being associated with inability. This does not only undermine their (CwDs) potential but also demeans them and compromises their development

of self esteem and a positive self concept. Consequently, when these children get to adult stage, they may resign themselves to self-pity and resort to begging on streets or depend on their kinsmen, neighbours, charity organizations and the state for their upkeep. It is through improving learning and development opportunities for CwDs, promoting and protecting their human rights like any other child, that they acquire knowledge, skills and attitudes applicable to their condition, so that they cope with societal demands both as children and adults later in life.

Conclusion

The study focused on types, care of CwDs and capacity of caregivers in providing their needs. Attitudes and perceptions of parents towards disability were also covered. Overall findings have shown that CwDs are denied care practices that promote mental stimulation and psychosocial development because of poverty, insufficient knowledge and skills about care of CwDs, lack of financial and material support, failure of parents to come to terms with the child's disability, cultural beliefs, negative attitudes, labels and stigmas. They have limited access to facilities and equipment (such as wheelchairs and hearing aids, among others). Consequently their fundamental rights such as education, health, love and protection are often compromised. Children with disabilities are, therefore, entangled in difficult circumstances which their able-bodied counterparts do not experience, hence their marginalisation.

Because of poverty, parents have difficulties creating an environment in which CwDs can thrive and realize their full potential. Chimedza and Peters (1999) say this undermines the opportunity to have children without severe disabilities weaned gradually from being totally dependent on their caregivers for both physiological and psychosocial regulation. In the same vein, parents should accord CwDs opportunities for interaction with able-bodied children and even adults. Lidz (1991) postulates that learning is a result of opportunity and experience. Consequently, when parents allow their able-bodied children to play, eat and share facilities, among others, they create learning and development opportunities for CwDs. More so, CwDs will have an appreciation of the realities of life that they would not achieve if they were left to learn alone as individuals. It should also be appreciated that CwDs also experience developmental urges such as to play, which have to be respected to enhance development.

It is important to note that most of the skills required to care for CwDs are difficult to acquire because CwDs are a special group. As a result, exposure of

parents to care of CwDs is fundamental as parents play a central role in providing for the needs of these children. In addition critical causes of childhood disabilities and support services such as referral centres have to be availed to parents so that they have an anchor to rely on whenever they are confronted with challenges in care of CwDs. Considering that CwDs in this study reside in rural communities that are marginalised, local schools should be assisted to purchase equipment and support devices/materials required for CwDs. These include wheel chairs, white canes, hearing aids, crutches, and tests, among others. This promotes creation of inclusive environments (EFA, 2000), which in turn increases access to education and learning opportunities for children with disabilities.

This researcher submits that it has to be noted that disability complicates life; not only of the CwDs, but also their caregivers. Disability is not therefore, an individual or personal challenge, but a shared one between CwDs and their environment. This 'symbiotic' relationship requires the environment to minimise psychological, geographical, economical and cultural obstacles, so that the disability challenges are manageable. This in turn creates an environment which CwDs can learn and develop that disability can be lived with, and by no means a condition that entails inability. Evans, Myers and IIFeld (2000) posit that to have a lasting influence upon the world one must invest in people's lives; and if one wants to maximize this investment, then one has to invest in those lives while they are still young. This researcher is concerned about 3-5 year old CwDs because they are part and parcel of the young generation. If CwDs continue to be marginalised, the Zimbabwean nation will lose part of the next generation and also sacrifice the future of CwDs. This suggests policy implications, which include recognising the plight of CwDs and the pervasive impact of poverty on their development, so as to employ informed intervention. Failure of society to be sensitive and responsive to the plight of CwDs will create a situation whereby CwDs remain the marginalised of the marginalised.

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