Responses, Coping Strategies and Needs of Primary and Secondary Caregivers of Children with Visual Impairments in Namibia: Teachers' and Parents' Perspectives

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Abstract

Since becoming signatory to the Salamanca Declaration in 1994, the Namibian education system has been battling with the implementation of inclusive education. It is taking the country a lot of efforts to move towards inclusive education approaches as the process is faced with various challenges including a lack of a commonly agreed upon conceptual understanding of inclusive education by stakeholders; lack of human and material resources and clinging to segregated approaches by stakeholders. One effort to implement inclusive education was to include learners with visual impairments in mainstream education systems. At the same time, special schools for learners with severe special needs continue to function and receive high preference from parents and caregivers. Teachers in mainstream schools do come across learners with visual impairments in their classes. In special schools into which learners with visual impairments are integrated, teachers also have the primary duty to teach all learners, including those with visual impairments even if they have not specialized in the field of visual impairment. While teachers have their own share of experiences related to their roles as teachers of learners with visual impairments, parents have experiences which influence their decisions to accord or withhold their children from education and social participation. In the current paper, which draws from two separate research exercises, one that focused on teachers' experiences and another on parents' experiences, primary and secondary caregivers share their experiences of caring for children with visual impairments through the narrative approach. The researchers simply represent and re-tell those stories.

Keywords

Introduction

The current paper explores first, caregivers' experiences of raising children with visual impairments and secondly, multiple roles of teachers of children with visual impairments and their perceptions of such roles in the Namibian education system. In the first part, a verbal sketch of the Namibian education system, accompanied by some main definitions and clarifications of terms, are provided. In the second part, caregivers'/parental views are discussed. These are followed by teachers' views and experiences of their roles as teachers of children with visual impairments within their educational and social contexts. The fourth part of this paper reports on the dual-methodology used to collect and analyze data. This will be followed by a presentation and discussion of the major findings as well as the key lessons learned from this dual-mode research. In the last part of the paper, recommendations and conclusions are made.

During the apartheid regime, there were limited provisions for children with special needs in Namibia. In the South African Education system, learners with special needs were educated in special schools. There were a few special schools which black children with special needs could attend. Shortly after independence in 1990, Namibia signed various Conventions and other undertakings to make sure that quality education is a right and is delivered in an accessible, equitable and democratic fashion to all children within the Namibian borders. One such convention, which directly has an impact on children with special needs, was the Salamanca Declaration (1994). The Salamanca Declaration makes it mandatory for countries to ensure that children with special needs be, as far as possible, included fully in educational institutions.There is political will to realize this expectation; however, its implementation is not free from challenges. The shift of mindsets from the traditional belief that special schools are the best form of provision for children with special needs serve as an impediment to inclusion (Haihambo 2010). Similarly, communities'negative views, coupled with long waiting lists of special schools make it almost impossible for the majority of children with severe special needs to access such schools, prompted the government to start looking at options to accommodate children with various special needs, as far as possible, in regular schools. At the same time, teachers in regular schools end up teaching learners with visual impairments by default and without adequate preparation and support for this task. The desired outcome for provision of

children with special needs, and especially those with visual impairment, is for them to be included in well-resourced and functional inclusive schools. The research being reported by this article has explored current responses, coping strategies and needs of caregivers (at home), as well as teachers' experiences of teaching learners with visual impairments.

1.   Brief background on Disability and Visual Impairment

The term visual impairments encompass a wide range of visual conditions and acuities. The World Health Organization (2008) defines blindness as acuity of less than 3/60 or a corresponding visual field loss in their better eye with the best possible correction. Low vision, on the other hand, refers to a visual acuity of less than 6/18 but equal or better in the better eye. Partial sightedness, in a Namibian context, indicates that an individual can see to a certain degree, but will need some adaptations to benefit maximally from educational programmes. Such adaptations may include enlarged text and orientation and mobility programmes. Children with severe visual impairments or who are blind need to be provided with learning material in Braille and tactual formats in order to access learning contexts. The implications of visual impairments on the cognitive, social and emotional development of children of all ages are widely recorded (Best 2000; Landsberg, Kruger and Nel 2010; Haihambo, 2010). It is commonly assumed that educational settings do not always take cognizance of these factors, leaving children with visual impairments to fend for themselves, and compelling caring teachers to act beyond their duties of teaching and provide pastoral care to learners with visual impairments.

Disability statistics in Namibia reveal that visual impairment is the second most prevalent disability after physical impairments (Central Bureau of Statistics 2004). According to the 2001 Population and Housing Census 37% of the total Namibian population was affected by Physical Disabilities; 35% with visual impairments; 21% with Hearing Impairments; 11% with Speech and Communication Impairments and 5% with Developmental and Intellectual Impairments. The 2011 Population and Housing Census indicates that the population size has grown from 1.8 mil in 2001 to 2.1 million in 2011 of which 51% are female and 49% male (National Statistics Agency, 2011:14). With regard to disability figures, the report indicates that 4.7% of the Namibian population has disabilities of which 5.7% live in rural areas and 3.3 %in urban areas. The next highest prevalent category of disability is physical impairment 33.6%.The second highest category of disability is visual impairment (Blindness 11.0% and other visual impairments 17.4%), amounting to 28.4 %.

Some results regarding children with disabilities

Statistical data obtained from the Ministry of Education reports indicate that 32 169 learners with disabilities wereenrolled in the education system in 2009 (Legal Assistance Centre, 2012). It is also revealed that a large number of children with other special needs

such as orphans and other children have been able to access education as provided for by the Namibian Constitution.

Table 1: Children with disabilities enrolled in the education system and type of disability

Type of Disability	Number of learners
Both Visual and Hearing	919
Partially Blind	4 309
Totally blind	196
Hard of Hearing	4929
Deaf	614
Epileptic	1331
Behavioural Disorder	5308
Mild Intellectual Impairment	3596
Severe intellectual impairment	1039
Physical impairment	1376
Learning Disorders	7057
Autism	316
Others (Unspecified)	1179
Total	32 169

Lifted from Legal Assistance Center (January 2012)

According to these statistics, 5424 learners attending school were affected by visual impairment.

According to research conducted in the United Kingdom, the past decade has recorded increased numbers of incidences of visual impairments in young children. These include mild forms such as short sightedness (myopia) to severe and profound forms such as blindness (McAllister and Gray 2007:839). It is believed that, in Western countries, provisions and concessions granted for children with disabilities, including visual impairments, in inclusive schools encourage more parents and children to seek assessments and disclose their disabilities. In Namibia, research has shown that the increase is attributed to widespread screenings but also to government disability grants, however insignificant the amount of disability grants may sound (N$ 200.00 per child per month)provided by the Government

of the Republic on Namibia for which a disability statement is needed (Haihambo, Brown and Tobias, 2011).

Currently, children with visual impairments in Namibia are either integrated or included in regular schools, or attend the limited special schools for children with visual impairments. There are ten (10) government special schools in Namibia. Only two primary, special schoolscater for children with visual impairments. It is expected, and has become a practice that more and more children with visual impairments are included in the regular schools for secondary education. In two secondary schools, the inclusion of children with visual impairments have been piloted and the program continue to ensure that children with visual impairments who, in the past were excluded from secondary and tertiary education can now complete secondary and post-secondary education. This process, however, is not without challenges.Some of these challenges will be explored in depth in subsequent sections of this article. At the same time, parents of children with visual impairments have their own set of difficulties which serve as impediments to inclusive education. The current paper aims to explore challenges of inclusive education from caregivers' and teachers' perspectives.

The current paper draws from two separate research projects:

- Research on caregivers' responses, coping strategies and needs of parents of children with visual impairments.
- Research on teachers of children with visual impairments in Namibian special, regular and inclusive schools. The sample of the study on teachers consisted of 10 teachers.

In both cases, a combination of purposeful and snowball sampling techniques were used to identify the most information-rich participants.

- Sample of main respondents per region for caregivers' research

Region	Number of caregivers
Caprivi	0
Erongo	10
Hardap	6
Kavango	2
Oshana	10
Otjozondjupa	10

Total of primary caregiver sample	38

Other participants sample for caregivers' research

Position/ Capacity of respondent	Institution of respondent	Sex of respondent	Number of respondents
Ophthalmologist	Katima Mulilo State Hospital	M	1
	Rundu State Hospital		1
Ophthalmologic nurses	Katima Mulilo State Hospital	F	1
	Windhoek Central Hospital		2
Teachers			10
Total number of respondents			44

Sample for teachers' research

Number of teachers	Type of School	Region
5	Inclusive school, secondary	Oshana
3	Special School	Oshana
2	Regular school with a special class	Khomas

2. Methodology

The researchers deemed it necessary to employ the qualitativeresearch design, to explore the phenomenon of caregivers' responses, needs and coping strategies with regard to visual impairments of children in their communities. These included a narrative inquiry approach, supported by in-depth interviews as its qualitative tools, to explore already identified as well as emerging issues that served as a window into the lives of families affected by visual impairments in Namibia. The teacher-research mainly utilized the narrative method. A qualitative, ethno-centric, descriptive, narrative design was employed to collect, present and construct meanings from the data. The qualitative design was deemed the most appropriate route mainly because the qualitative researcher uses multiple voices and sources to bring across the main messages. Through this polyvocality,

the researcher strives to "convey naturalistic, complex, varied, expansive and caphonous" meanings, and even include the silences between the multiple voices (Thody 2006: 109). In both researches, the qualitative design was used, with the primary aimofcollecting, presenting and analyzing multiple data through multiple voices and retaining these voices through the narrative inquiry technique.

3. Data collection methods

3.1 Narrative approach: There are three main outcomes of narrative research:

"First, narrative research is concerned with individual lives as the primary source of data. Second, it is concerned with using narratives of the self, as a location from which the researcher can generate social critique and advocacy. Third, narrative research is concerned with deconstructing the "self" as a humanist conception ..." (Bloom 2002: 310). While narrative research appears to be the most relevant form of collecting primary data 'from the horse's mouth', there are common challenges that researchers using it should be aware off Bloom (2002: 310). Narrative format is oldest form of transferring knowledge in Africa and the researchers have noticed the comfort with which this form of research is generally accepted as opposed to questionnaires and interviews., tells of a feeling of invading into the respondent's privacy, and "opening wounds" (Bloom 2002: 312). However, she further argues that these challenges are both personal and contextual. In the case of this study, the researchers were confident that their knowledge of Namibian cultures, languages and history, coupled with their experiences as educators in secondary and special schools and later in an institution of higher education, helped them overcome such possible challenges, and other barriers of narrative research.

As a qualitative approach, narratives are said to bridge the gap between researchers, their respondents and the content they create, more than quantitative and statistical methods can ever do (Roberts 2002: 119). Josselson (1995) in Roberts (2002: 120) summarizes narratives as follows:

"Narrative models of knowing are models of process in process. When we record people's narratives over time, we can observe the evolution of the life story rather than see it as a text in a fixed and temporal state. As a novel leads inevitably to the end, personal narrative describes the road to the present and points the way to the future. But the as-yet unwritten future cannot be identical with the emerging plot and so the narrative is revised" (Roberts 2002: 120).

In both sets of research, the narrative, ethnocentric research was mainly used to collect data from carefully selected individuals. Purposive, snow ball sampling techniques were used to arrive at information-rich potential respondents.

3.2 Open-ended narrative interviews

According to Schostak (2006:10), the interview can be described as a tool through which the interviewee and the interviewer direct their attention towards each other with the aim of gaining insight into the "experiences, concerns, interests, beliefs, values, knowledge, and ways of seeing, thinking and acting of the interviewee."

Cohen, Manion and Morrison (2000:269) define the interview as a two-way conversation initiated and facilitated by the interviewer for the purpose of obtaining information relevant to his or her research. It entails direct verbal interactions between individuals. They further argue that while the interview offers opportunities for depth, it also opens itself up to researcher bias. The interview thus requires that researchers demonstrate academic maturity and not manipulate the data in the way they would like. In both cases a narrative interview served a dual purpose: listening to interviewees with a therapeutic ear. To collect firsthand information from people who live in the milieu being researched and learn about the topic through the eyes of the respondents.

4. Presentation and Discussion of findings

This section will provide a bird's view discussion of findings first from the perspective of parents and secondly from the perspective of teachers.

4.1 Section 1: Parents' views

Parent's views are discussed under five major themes.

4.1.1 Initial reactions

Discussions with the above key respondents revealed that there was a general negative connotation to disability in general and visual disability in particular. Due to this negative connotation, parents and families of children with visual impairments found it very hard to accept and deal with the reality of visual impairments among their children. They feared the manner in which they would be perceived by their communities, which contributed to extreme stress and grief upon discovery or confirmation of visual impairment in their children. One of the respondents revealed that in his particular community, visual impairment was associated with witchcraft. This means to say that

if a parent has a child born with severe visual impairments, there is an assumption that they practiced witchcraft in order to increase their harvest and get rich, and this backfired. Hence, such parents felt shame and would normally take such children to a faraway village and leave them there with the grandmother (Haihambo & Lightfoot, 2010). Often, such children were not taken to school when they reached school-going age, because they were regarded as lacking the potential to learn and pursue careers in future. A number of respondents across the regions narrated grief using descriptors such as *"I felt like my life had come to an end"* (severity of disaster); *I cried and cried for days until one of the nurses took me to a children's ward where I saw children with much worse conditions"* (lack of acceptance and importance of relevant intervention); *"my daughter came to drop the child with us, left and never to set foot here again* (fleeing from a difficult situation and delegating it to grandparents) and *"at first I was scared of the child because she is ethithi (albino). After a few months, I left him in the village with my parents but when I went back and saw how neglected **my** child was, I decided to* **take my child** *and moved with him to Okahandja"* (fleeing, but with the child to a place where nobody knows them). This was one of the cases where the researchers noticed a strong claim of ownership (my child) but not without challenges and emotional battles.

The initial responses in the different regions ranged from heartfelt pain, self-rejection, despair, shame and fear of the unknown. Amongst the 10 caregivers interviewed in the Erongo region, six revealed that they were shocked and very hurt. Almost all respondents revealed that they cried for days upon discovery of their children's visual impairment. Two took their children to health centers for assessments and intervention; and two decided to pray and wait for God's guidance and divine intervention. As time moved on, almost all respondents accepted the visual impairments of their children as the will of God.

This was how some caregivers articulated their initial responses:

"I was worried that he will lose his sight, I actually started shivering when I have confirmed that he bumps into objects all the time."
(Mother 38, Otjimbingwe).

"Villa was born prematurely and did not grow well. At around age one, we saw that his right hand was hanging and his right eye also only faced in one direction and with no blinking. We went to the doctor but he said we should come back when he is a little older. We went when he was five and were referred to Windhoek. The doctor said he has brain damage. He was born too early and the nervous system was not fully developed. Then he only said we should go back home and take good care of him. He also advised

us to keep bringing him back for physio [therapy] and give him nutritious food. I felt
numb in my legs, and there was something hard in my throat. But I just had to accept
"kutyananiondavalaokanonaokalema(that indeed I have produced a disabled child)"
While we were in Windhoek, I saw other mothers who have children whose disabilities
are worse than mine. Now I am OK. At least the children spend mornings at Center for
Children with Disabilities (CHAIN) and I do not have to focus on him all the time."
(Mother, 27, Mondesa).

There seemed to be a different perception regarding acquired visual disability as opposed
to congenital conditions. When the visual impairment was acquired, parents felt sad and
pitied themselves. They were also pitied by their communities as though they were struck
by disaster that would jeopardize their lives forever. In contrast when it is congenital
impairment, the occurrence of visual impairment was accepted as a natural occurrence,
with many regarding it as "the will of God".

When asked about interventions or actions taken following initial reactions to the
discovery of visual impairment, many key respondents revealed that primary caregivers
did not always seek medical assistance. Some reverted to traditional doctors who often
used traditional medicine and provided traditional explanations which did not always
provide the required results. A surprising element was that in four out of seven regions,
many parents and caregivers only sought medical assistance in order to get certification
that entitled them to the disability grant provided by the Ministries of Health and Social
Services as well as Gender Equality and Child Welfare.

A major reason of seeking assistance from the health facilities was the disability grant.
In order for one to access the disability grant provided by the state for children with
confirmed disabilities, one needs a medical report as well as a report from social workers.
State ophthalmologists indicated that they made use of opportunities like these to carry
out thorough assessments and advised parents and caregivers about the care for children
with visual impairments as well as to regularly visit health facilities for the monitoring
of their children's visual conditions and interventions. Asked about the process followed
when a child was born with visual impairments in hospitals, respondents (medical
personnel) explained that such babies were referred by pediatricians to eye-specialists
for thorough examinations. This made early detection and early intervention easier.
For conditions such as cataracts and other correctable conditions, primary caregivers
were offered available solutions, including corrective operations offered by the state in
collaboration with donors. Medical personnel also revealed that they made use of field
operations or eye camps to provide information about visual impairments and different
eye conditions. In these campaigns, they focused on prevention but also used these to
identify people in the communities who needed interventions by way of corrective surgery.
Through these processes, a lot of people regained their eye-sight and these served as

symbols of restoration of trust in the health system. Sadly, respondents noticed that once people were registered and were receiving the disability grant, some were reluctant to utilizesightrestoration opportunities as it would mean that they would forfeit the grant. Surely, this fact addresses the degreeto which poverty has affected communities to the extent that some people would deny their children opportunities to have their eyesight recovered for the sake of grants, which range between two hundred and two hundred and fifty Namibian dollars (N$ 200-00 – N$ 250.00) per child per month.

Sadly, for those who have eye-conditions that were more permanent, one respondent said, *"We tell them that there is nothing we can do for their children. They should go home and take good care of their children by providing them with good nutrition, preventing accidents and accepting their visual impairments"* (Ophthalmic nurse, Kavango region). This message could have serious implications as many caregivers might interpret such messages to mean that the health system has failed them. They therefore are likely to revert to traditional solutions which might further jeopardize the general health and the visual conditions of their children with visual impairments as well as cause conflict between community members as in many cases their explanations tend to refer to others as having caused the condition in question.

The data clearly revealed the importance of information, counseling and other related support systems in accepting children's disabilities and other health conditions. It is also important to mention that belief systems and comfortability with the impairment have a likelihood of enhancing or impeding inclusive education.

4.1.2 Difficulties associated with raising children with visual impairments
This question yielded emotions: sadness, pain, despair and perseverance. In most cases, researchers had to engage in "counseling" before continuing with the interview. This demonstrated that the difficulties experienced by caregivers of young children with visual impairments were overwhelming and sometimes beyond the coping capacities of respondents and their families. Almost all respondents mentioned financial needs to be able to ensure a better standard of life for their children with visual impairments. Only in one case did a respondent say: *"We do not need anything except for the community to leave us alone because we do not ask anything from them for our child!"*(Mother, 34, Oshana region).In this statement, the respondent refers to stigma attached to disability and expressed the wish to be left alone.

4.1.3 Concerns over the child's future
For the majority of respondents in this study, the future of their children with visual impairments was something they never thought of. It was as though they had perceptions that such children have no future besides being taken

care of until they die. Primary caregivers across regions almost reacted in the same way when asked about schooling options for their children, with some indicating that they never knew that children with visual impairments could go to school, and others knowing about special schools which most of them found either too far and/or too expensive.

This is how one mother responded:

"Will she be able to go to school? I am fine because the pre-school she goes to is fine having her. She sits and plays with other children. They only sing and play and learn to count. How will she learn in school?" How can she read from the chalk board or write in a book?" (Mother, 26 year old, Usakos).

The above response, which was common in areas without special schools, was indicative of lack of exposure to schooling opportunities for children with visual impairments. This response also implied that a lot still needs to be done in the area of de-stigmatization of disabilities and the rights and opportunities of education for children with disabilities in accordance with the Convention of Rights of Persons with Disabilities (2010), the National Policy on Person with Disabilities (1997) and National Policy on Inclusive Education for the Education Sector (2012).

In Otjozondjupa region, a 78 year-old grandmother who was advised by community rehabilitation officer to take her child to a special school in Windhoek about 450 kilometers away from their home had the following to say:

"G will go nowhere. He will stay here with me until my eyes close and the sand on my grave is level! When one of the researchers prompted by asking (and then, what will happen after you are no longer around?"), the respondent thought for a while and said, *"Then the mother will have to come fetch him!"*

This particular interview also revealed lack of awareness of options for children with visual impairments, lack of knowledge and trust in the system to take care of these children whom the primary caregivers believed to be their God-given burden and thus only they can take good care of them as well aslack of effective models of other care and education options for children with visual impairments.

In regions like Erongo that had two major centers targeting the education and social welfare of children (Sunshine Family Center in Walvis Bay and the CHAIN Center in Swakopmund), primary caregivers regarded these as central representations of support as will be seen in the next theme. However these centers represented segregation as opposed to inclusive education. Good models of inclusive education remained evasive throughout the research. Where inclusive education models were attempted, they were met with social, infrastructural and resource barriers.

4.1.3 Support from other sources

Respondents demonstrated gaps in the national as well as community support systems for parents and caregivers of children with disabilities in general and visual impairments in particular. Some respondents yearned for the presence of their mothers and grandmothers as they struggled to cope with their children's visual conditions. Others bemoaned the absence of counseling after or during disclosure; the absence of care and support facilities for the children, financial and other forms of support and their consequences as explained by respondents below: One respondent had the following to say:

> *"We could have taken him to private doctors for thorough examinations. This way, we would know for sure what is wrong with his eyes. But we cannot afford them."* (Mother 47 years old, Otjimbingwe).

Yet another caregiver had the following to say about support:

> *"We went to the doctor and they prescribed glasses. The Center where she goes in the mornings helped us with all these. Before this, it was not easy for her. I used to feel sorry for her when she played with other children who could see all the dangers while she can't. But now with glasses it is much better. But we do not allow her to wear the glasses at home. She is naughty and she will break them in the process of playing. They run around and throw things at one another. We cannot afford another pair of glasses if these ones break."* (Mother, 29 years old, DRC).

In a rather extreme case, the absence of support could lead to stress as explained below:

> *"There are no positive aspects from raising Candara. She creates stress from one day to the other. I pray to God that she dies or I die...I can't take this any longer"* (Mother, Hardap region).

The issues in this theme point to a lack of coordinated interagency collaboration. In cases where support was evident, parental stress was reduced and the quality of interaction between the primary caregivers and their children with visual impairments was positive. On the contrary, the absence of support yielded negative emotions and frustrations which were detrimental for both caregivers and children. The lack of support also had negative implications for children with visual impairments' chances to attend any form of school, let alone inclusive education.

Where support centers were available, parents and caregivers upheld and hailed them for the services they render, providing much needed services, while relieving parents from constant care, at least for certain hours of the day. Centers such as the CHAIN in Swakopmund and Sunshine Family Centre in Walvis Bay were often described by respondents as "their lifeline". Respondents often found these centers as a "place of relief" as many explained that children are collected from home to school and dropped back; if they need assistive devices, these are arranged by the centers and one caregiver stated:

> "The center where she goes in the morning is what keeps me in this town. They give us information and they know how to care for these children. They pick her up and drop her back in the afternoon. Sometimes they even pack them some food and extra nappies." (Mother, 42 years old, Swakopmund).

> "When the child is fetched, I get time to go buy the products I sell from our house." (Mother, 38, Swakopmund).

This statement demonstrated how support centers served not only as education and social welfare institutions, but also as secondary caregivers allowing primary caregivers breaks from their overwhelming duties of caring for children with disabilities.

While some relied on Centers, which offer limited spaces, others relied on various community structures for support, as explained by this respondent:

> "I started attending church and they prayed for me. The members of the congregation always ask how we are doing and they also collected money to enable us to travel to Windhoek to see the eye-specialist" (Mother 42, Swakopmund).

4.1.4 Expressed needs from communities and societies

Most respondents indicated behavior or attitudes they disapproved of in their communities and schools for example:

> "Teachers used to be insensitive. They could see my child was sitting in front covering his one eye with his hand while trying to write. Yet they would ask: 'Why can't you write properly? What's wrong with you?' I went to the principal and told him to get those teachers of my child's case. And this new principal of us does not take nonsense. He addressed it" (Father, 42, Erongo).

> "We just want society to accept and stare less. It causes great uncomfortability."
> "Jackson is still small. I just hope that when he grows up that people will not mock with him. It's not something he asked for."
> "I don't want anything specific from my community, they should just accept Rivaldo."
> "I don't need any support from the community because they are negative towards my child. I want them to stop gossiping..."
> "This is God's work and I need the church to support with spiritual teachings and prayers. I don't want society to reject my little girl because of her sight problems and condition with her eye." (Aunt, 33, Oshana)

Stigma and discrimination were central in the experiences of the respondents of these research studies. Unless these issues are addressed, progress in terms of an inclusive society is likely to remain fruitless.

4.1.5 Difficulties associated with raising children with visual impairments

Respondents explained at length how they toiled from day to day to raise children with visual impairments without sufficient support structures in place. Their difficulties ranged from financial limitations, lack of technical-know-how, community viewsand lack of psycho-social support in terms helping parents and caregivers overcome the grief of their children's disabilities.

Primary caregivers who have children whose visual impairments co-exist with other impairments expressed more difficulties than those with isolated visual impairments.

"I am coping with difficulties, although I thank God that I have my sister who is there for us both for financial and spiritual support. Raising a child with visual impairment without the father's support [financial] is very difficult" (Mother 38, Otuzemba, Opuwo).

"We need induction on how to help him to interact with others; information on how to get admitted to special schools where there are people with similar disabilities and stimulative toys" (Mother 27, Oluvango).

"Counseling and training for the family to accept the child. I did not receive any counseling. My advantage is that I have visual impairment myself. My mother also never received counseling when I acquired visual impairment" (Mother 28. Ohongo village).

"We need money to keep him in school. I also need encouragement to continue caring for my child" (Mother 34, Okandjengedi- south).

As demonstrated by the responses below, acceptance of having a child with a disability in a society where disability continues to be highly stigmatized, posed various challenges to primary caregivers. Also the lack of basic needs, lack of information regarding schools for children with visual impairments and community interventions and programmes impact the degree to which primary caregivers are able to provide sufficient care for children with visual impairments. There were no significant differences between regions sampled for the studies. The only factor that posed a large difference was the presence or absence of institutions rendering support and accommodating children with visual impairments and their caregivers. Finally, researchers did not have an opportunity to observe early childhood and primary schools practicing inclusive education. Where children with visual impairments were included in schools, it was either in the form of special schools or special classes, or inclusion by default, in which cases planned efforts to support these children in terms of learning and socialization support were insufficient. This section is concluded with an observation that community-based programmes targeting parents, children and their communities will go a long way in demystifying and de-stigmatizing visual disabilities and promoting inclusive education practices.

4.2 Teachers' views of teaching children with visual impairments

The second section presents and discusses findings from research with teachers of children with visual impairments in settings as described above. Ten teachers (secondary caregivers) of children with visual impairments participated in this study. Two of them had profound visual impairment (legally blind).

From the onset, researchers in this section departed from the understanding that children with visual impairments have unique characteristics and where these children were included, learning and teaching will be in vain if these characteristics were not considered.

The researchers assumption as stated above were confirmed by the American Foundation for the Leadership Institute, Education, 2000) who maintained that students with visual impairments have unique educational needs which are most effectively met using a team approach of professionals, parents and students. In order to meet their unique needs, learnermust have specialized services, books and materials in appropriate media (including braille), as well as specialized equipment and technology to assure equal access to the core and specialized curricula, and to enable them to most effectively compete with their peers in school and ultimately in society.

They further emphasized the importance of a full range of program options and support services so that the Individualized Education Program (IEP) team can select the most appropriate placement in the least restrictive environment for each individual learnerwith a visual impairment.

Another requirement of inclusion is adequate personnel preparation programs to train staff to provide specialized services which address the unique academic and non-academic curriculum needs of students with visual impairments. There must also be ongoing specialized personnel development opportunities for all staff working with these students as well as specialized parent education(The American Foundation for the Leadership Institute, Education, 2000)

Teachers who participated in this research were either teaching in special schools, special classes or inclusive primary or secondary schools in Namibia. Data was collected through narrative interview methodology in which they were asked to narrate their day to day experiences of teaching children with special needs. Although they were not asked to talk about challenges, respondents' discussions were dominated by their daily struggles of teaching and supporting children with visual impairments.

The findings are presented under the following themes:

4.2.1 Multiple roles of teachers of learners with visual impairments
Respondents revealed that, although they were appointed on the same terms as their colleagues and received the same salaries and other benefits, teachers who taughtchildren with visual impairments performed roles that

wentbeyond those of their peers with regard to time spent on issues that have direct and indirect bearing on the learning and socialization of learners with visual impairments. Like any other teachers, their primary roles were those of teaching all learners, including those with visual impairments. This role involved preparation for classes, teaching, marking, supervising students' intra- and extra-curricular activities and any other role deemed necessary by school principals, inspectors or Head Office officials. Respondents revealed that, in the process of recognizing the unique needs of children with visual impairments, they often found themselves working long hours preparing for the inclusion of learners with visual impairments. They always had to go an extra mile in developing teaching and learning aids and adapting them to the various levels of visual acuity of their learners, learning and managing technology and ordering needed material. They expressed the frustrations they experienced, especially with regard to the treatment they received from their line managers (heads of departments and school heads) who clearly did not understand or value their efforts. While they did more work than their peers, they did not seem to receive enough support from stakeholders. In particular, teachers who were blind themselves were not allocated class assistants as the staffing norms of the Ministry of Education did not make provision for these. They relied on colleagues to help when they could. During busy times like examination times, support from colleagues was hard to come by and they were often frustrated. The absence of appreciation was obvious through all the interviews. Most of the respondents reported that, despite their endless efforts, they were made to feel that they had to deal with their situation and were not supported in any way. Instead, they were often blamed for learners' failures (by parents and education authorities), with little acknowledgement for what they had to deal with on a daily basis.

The second role identified by respondents was that of **advocacy**. Often, respondents had to become involved in negotiating for concessions and acceptance of learners with visual impairments like one respondent added *"as if they are our own children and they are there for our own benefits"* (Female social sciences teacher, inclusive secondary school).

Another teacher shared the same sentiments as summarized in this statement: *"I feel like I am begging for favors for these children all the time. Some of my colleagues even say :'you are protecting those children of yours again!"* (Female Geography teacher).

Respondents maintained that the piloting and implementation of inclusive education at their school should be the role of school management. They

were of the opinion that management should accept responsibility for the administrative duties of inclusion and they should simply teach like all other teachers did. The ordering of material and assistive devices; making special arrangements for invigilation and examination papers and even developing teaching and learning aids should be shared by management and themselves.

Respondents were clearly unhappy with labels assigned to them by their colleagues, with some even claiming that they *"think like your students!"* Respondents found this derogatory and contradictory to their school's mission of working as a team towards the joined successes of their learners.

Not only did the general teaching corps lack interest in cooperating and supporting learners with visual impairments, but some were ignorant towards the needs of learners with visual impairments. Some were also reported patronization of learners by teachers and peers and in some cases bullying has been reported. This compelled teachers to raise these issues of bullying, dehumanization stigmatization continuously during staff meetings and assemblies with learners. This finding is supported by the Ministry of Education, 2008 who confirmed that often learners leave school due to negative views of peers or teachers. Respondents maintained that, some of their colleagues tookheed of the advice and asked for more advice when facing challenging situations in their classes, but others felt that teachers who have been teaching learners with visual impairments acted out of their place by following up complaints and giving advantage of doubt to learners with visual impairments.

The role of coordination and facilitation

Respondents revealed that because they taughtlearners with visual impairments, they spend a lot of time with these learners and thus become more aware of their needs. This knowledge automatically leads them to become messengers and advocates for the needs of learners with visual impairments. They maintained that this too should be the responsibility of school management to oversee the fluent implementation of inclusion by putting structures in place by which learners will express their needs and have them addressed through official school channels. One teacher had the following to say:

"Although we were trained at workshops not to get personally involved in learners' needs, the implementation is more challenging than theory. If a learner tells you they have not had food for days, or they do not have soap and you can even smell that they have not bathed, what will you do? Or a learner who is blind tells you that they have a test and do not have the notes, will you just say: 'Sorry, good luck with your test?' No. I go out of my

way to make sure the learners have the copies they need. You end up opening your purse or fetching soap or bread from home and give it to the learner. And do you think the principal will say, let us refund you for that using the school development fund? No. Instead, you are blamed for helping" (Primary special school teacher).

Another teacher narrated how learners complained about not gaining from other teachers, forcing them to either approach those teachers or the head of department for support. Unfortunately, learners reported that both actions were regarded as offensive by those teachers:

At one point learners with partial visual impairments, came to me and told me that a particular teacher continued to use small print on the chalk board, refused to give printed notes to them and continuously told them to borrow books from others. This teacher kept telling the learners when they requested for notes that nobody told him that he wouldbe teaching blind learnersand neither didhe have skills to do so. I first informed the Head of Department who did not take any action and the learners started panicking as examinations were approaching. I have tried to explain to the teacher in a friendly manner that he was disadvantaging learners and should go to the resource teacher at the school to make special provisions for learners with visual impairment. But the teacher took offense and told me that he was better qualified than I am so I should keep my nose out of his affairs. So what do you do? Back-off and let the learners fail or get involved in conflicts with staff members?"

The role of teaching entails understanding all children, and preparing for all children. In an inclusive setting, this requires creativity and knowledge in inclusive skills. If these knowledge and skills are not shared by all teachers, and support is not given to all, it may lead to conflicting situations emanating from some teachers feeling that they are being exploited and others viewing advice from others as bossiness.

Respondents in this study expressed frustration with regard to absent support structures from school level up to Head Office and regional level. Some respondents maintained that inclusive education was dumped on them and forgotten. Respondents in all schools involved in this research observed that there were no school-based policies to support teachers of learners with visual impairments and that teachers were left to fend for themselves while the work they were doing was not their private affair.

One respondent exclaimed: *"Ministry of Education does not always deliver what they promise, making teaching more complex"*.

Yet another teacher had the following to say regarding perceived non-commitment from authorities:

"The manner in which GRN (Government of the Republic of Namibia)and specifically MoE (Ministry of Education) pay lip-service to inclusive education is disturbing! Question papers arrive with flaws; machines (braille) are not serviced regularly; support teachers are not appointed on a full-time basis; Brailed papers sent for examination get lost and learners have to repeat grades. We make the same requests again and again. I am the lonely voice in the desert!" (Burn-out). (Male Head of Department, special school).

4.2.2 Non-recognition of additional roles

An overwhelming majority of respondents felt that they did not receive any recognition for their hard work in making the inclusion of children with visual impairments a success. On the contrary, some felt that they were being punished because often, school principals did not acknowledge them personally or in public; their names were not sent to regional office as those who go an extra mile; they did not receive any incentives; and they received the same salaries as those who did not do anything extra. A degree of both frustration and burn-out was observed amongst respondents with some indicating their intentions to change to schools where they too could go and rest.

A female teacher in a school with a special class had the following to say:
"When it is prize giving, our learners or teachers are forgotten. No good word to us. No piece of paper to encourage us. Our class is at the back of the school as if we suffer from a contagious disease and we are only mentioned to visitors who come to the region regarding inclusive and special education issues. Even teachers of regular learners keep saying we do not have a lot of work like them. Do they even know what we have to deal with?"

4.2.3 Lack of training in inclusive education and induction

Out of eight respondents, only two received training on the conceptual understanding of inclusive education. This information was acquired through pre-service, formal teacher education at the University of Namibia. However, respondents also hastened to mention that their training was theoretical and lacked the practical aspects of inclusion. They claimed that practical sessions were too limited to prepare them for what they encountered once they were appointed to serve as teachers in special or inclusive schools.

Respondents maintained that the bulk of their knowledge was learned from actual teaching in schools. The remainder of the respondents learned about inclusive education when they encountered learners with visual impairments in regular schools. Some found the concept alien and not suitable in Africa, while others maintained that, if planned well, inclusive

education will go a long way in doing away with negative viewstoward persons with disabilities.

Respondents also indicated that schools lacked induction programs for teachers of/ with learners with visual impairments, and for learners with visual impairments. They believed that a lot of learning time was wasted while both learners and teachers were learning the ropes of teaching, learning or functioning in inclusiveschools (Josua, 2012). They added that most of the schools were not built for learners and teachers with visual impairments and the lack of induction and mobility training prolonged adjustment periods and impacted learning and teaching negatively. Respondents, maintainedthat with exception of two, most of their institutions have been in the business of teaching learners with visual impairments for more than 15 years and should by now have organized induction programs. They noticed that every year, schools responded to learners with visual impairments as if they did not expect them.

It was recommended that teacher-education institutions forged closer links with schools for learners with visual impairments and ensures that students acquired practical skills such as Braille and mobility skills prior to their graduation. This would help novice teachers when they are appointed at schools for learners with visual impairments.

4.2.4 Lack of positive parental and community involvement

Respondents (secondary caregivers) narrated stories of parents/ primary caregivers who brought their children to school at the beginning of the year and left, never to come back. Some parents had to literally be called or be invited through radio messages to come and collect their children for school holidays.

This is what one of the teachers in a special school had to say:

> "They hand-over their children to the school in January and never come back. Even for school holidays and out-weekends, we literally have to beg them to fetch the children."

Some parents were also reported to have negative expectations of the educational potentials of their learners. This was reflected in learners' reports to teachers that their parents claim that they are wasting time at school as they cannot become useful members of their society due to their impairments.

This finding confirms what the data on primary caregivers revealed: those primary caregivers who had difficulties accepting their children's visual impairments and had insufficient support, found association with their children stressful.

4.2.5 Frustration and joys

When asked about their frustrations and joys, respondents maintained that they did not mind being watch dogs for learners with visual impairments. They regarded themselves as having become experts in the field. They have become more aware of cultural myths regarding disabilities and were happy to play a role of demystification. They found joy in meeting learners whom they have taught and are pursuing higher education or jobs.

Describing the down side of their roles, respondents reported thatthey were often frustrated by lack of specialized training, lack of support and lack of acknowledgement which made their task more daunting than it should be.

Teachers who teach learners with visual impairments performed multiple roles in which they experienced both joys and frustrations. Teachers who take it upon themselves to assume these roles are both seasoned and novice – no expertise needed, except for a caring heart.

They experienced barriers to inclusive education which were largely administrative in nature and could easily be addressed through the development of pro-inclusion policies.

It is also recommended that school managements should take charge of the implementation of inclusive education policies in their schools, by so doing reducing pressure the process posed on willing teachers in special and inclusive schools.

4.2.6 Conclusions and recommendations

Negative views and perceptionsof learners, teachers, parents and institutional workers were patronizing and often degrading. Learners with visualimpairmentswere under-estimated academically by peers, and teachers.Willing teachers who have assumed the role of supporting students and teachers were often overburdenedand labeled. They experienced frustration and burn-out as they had to address the same issues again and again: inclusion is thus not an internalized philosophy.

Even in special schools, discrimination was based on the nature and severity of disability. Learners with residual vision tend to look down on those who are blind. Teachers were often caught in conflict resolution and sensitization efforts which drain their energy that should have been directed to teaching and learning.

Inclusive education remains alien to many primary and secondary caregivers of children with visual impairments. Teachers, who were educated and trained, also do have inhibitions informed by negative viewstowards persons with visual impairments. This has implications for sensitization programmes for the care and education of children with visual impairments. As it is currently, many parents and caregivers were not aware of inclusive or special schools. Those that were aware didnot have enough trust in the system or undermined the education potentials of children with special needs. There is need for models of care that work. In this study, Centers of Care have proven to be a good intervention for parents, but care has to be taken to ensure that parents do not only use the centers as places where they can leave children while they rest or do other things, but that they become involved to the degree of acquiring skills and passing them on to others.

Interagency collaboration, including all stakeholders, is needed to ensure that all parties involved in the education of children with visual impairments receive the necessary support they need in order to make the process a success for everybody. Parents and caregivers as well as teachers and learners are all key stakeholders to the wellbeing of learners with visual impairments.

References

American Foundation for the Blind (2009). Expanding Possibilities for Visual Loss.AFB.

American Foundation for the Blind's (2000). Leadership Institute Education.

Best, J. W. & Khan, J. V. (1998).Research in Education.8th Edition. Alan & Bacon.

Bloom, L. R. (2002). From Self to Society: Reflections on the Power of Narrative Enquiry, in *Qualitative Research in Practice: examples for discussion and analysis*, edited by S. B. Merriam & Associates, San Francisco: Jossey-Bass: 310 – 313.

Bronfenbrenner, U. (1979). *Ecology of Human Development: Experiments by Nature and Design*. Cambridge. Harvard Press.

Clandinin, J. D. & Connelly, M. F. (2000). *Narrative Inquiry: Experience and Story in Qualitative Research*. San Francisco. John Wiley & Sons.

Clandinin, J. D. (Ed). (2000). *Handbook of Narrative Inquiry: Mapping a Methodology*. Thousand Oaks. SAGE.

Cohen, C., Manion, L. & Morrison K. (2007). *Research Methods in Education*. 6th Edition. London. Routledge.Taylor and Francis.

Cohen, C., Manion L. & Morrison, K. (2000). *Research Methods in Education*. 5th Edition. London. Routledge Farmer Taylor and Francis.

Creswell, J. W. (2007). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. Thousand Oaks. SAGE.

Denzin, N. K. and Lincoln, Y. (Eds).(2000). *Handbook of Qualitative Research*. 2nd Edition. Thousand Oaks. SAGE.

Department of Education.(2001). *Education White Paper 6*. Office of the President. Pretoria. Rustica Press.

De Vos, A. S. (2005). Combined Quantitative and Qualitative Approach. In *Research at Grassroots for Social Sciences and Human Service Provisions* edited by A. S. de Vos et al, Pretoria: Van Schaik :363- 365.

Flanagan, N. M., Jackson, A. J. & Hill, A. E. (2003). Visual impairment in childhood: insights from a community-based survey. *In Blackwell Publishing Ltd, Child: Care, Health & Development* (29, 6) 492 – 499.

Glidden, L. M. &Natcher, A. L. (2009).Coping strategy use, personality and adjustment of parents rearing children with developmental disabilities. In Journal of Intellectual Disability Research Vol. 53 (12) 998 – 1013.

Government of the Republic of Namibia (2007).National Integrated Policy of Early Childhood. Ministry of Gender Equality and Child Welfare.

Haihambo Ya-Otto, C. K., February, P. J., Brown, A. & Hengari, J.U. (2009). Responses of Vocational Training Institutions to Inclusive Education in Namibia. A Paper presented at the SANORD Conference on Inclusion of the Excluded, Grahamstown, South Africa.

Haihambo, C. K. (2010). Inclusive Education: Challenges of Students with Disabilities in Higher Education Institutions in Namibia. A doctoral dissertation for the University of South Africa.

Hill, C. & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. In *Journal of Intellectual Disability Research*. Vol. 53 (12) 969 – 980.

Josua, L. M. (2012). *Challenges of Inclusive Education for Management of one Inclusive School in the Oshana Education region*. A Masters' thesis presented to the Faculty of Education, University of Namibia. Unpublished.

Klein, P. S. (ed.)(2001). Seeds of hope: Twelve Years of Early Intervention in Africa. Oslo. Unipubforlag.

Kiegelmann, M. (Ed.) (2002). *The Role of the Researcher in Qualitative Psychology*. Germany. Ingerborg Huber Verlag.

Landsberg, E., Krüger, D. & Nel N. (Eds)(2010). Addressing Barriers to Learning: A South African Perspective. Pretoria. Van Schaik.

Legal Assistance Center (2012). *Alternative Report to Namibia's first, second and third periodic reports on the implementation of the Convention on the Rights of the Child and two optional Protocols.* Gender Research and Advocacy Project, Legal Assistance Center.

Lennon, J., Harper, R. Lloyd, C. &Biswas, S. (2008). Usefulness of post-assessment reports in a pediatric low vision clinic: a questionnaire survey of parents and education professionals. In *Ophthalmic and Physiological Optics*. Volume 28 (3)247 – 252.

Lloyd, T. J. & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. In *Journal of Intellectual Disability Research* Vol. 53 (12) 957 – 968.

Merriam, S. B. & Associates (2002). *Qualitative Research in Practice: examples for discussion and analysis*. San Francisco. Jossey-Bass.

Merriam, S. B. (1998). *Qualitative Research and Case Study Applications in Education*. A Francisco Jossey-Bass.

Mertens, D. M. (2005). *Research and Evaluation in Education and Psychology: Integrating Diversity with Quantitative, Qualitative, and Mixed Methods*. 2nd Edition. SAGE.

Ministry of Education (2008). *The Development of Education Report*. Ministry of Education.

Mushaandja, J. (2007). Investigating Professional Development Needs of Secondary School Principals in. Doctoral dissertation.University of the Western Cape, Cape Town.

Neuman, W. L. (2003). *Social Research Methods: Qualitative and Quantitative Approaches*. 5th Edition. Boston. Allyn& Bacon.

Rye H. (2001). Twelve Years of Early Intervention Studies in Ethiopia in Klein P. S. (ed.) (2001). Seeds of hope: Twelve Years of Early Intervention in Africa. Oslo. Unipubforlag.

Klein, P. S. (ed.)(2001). Seeds of hope: Twelve Years of Early Intervention in Africa. Oslo. Unipubforlag.

Klein, P. S. (2001) *A Mediational Intervention for Sensitizing Caregivers in Klein P. S. (2001) Seeds of hope: Twelve Years of Early Intervention in Africa*. Oslo. Unipubforlag.

Republic of Namibia (2011). Namibia 2011 Population & Housing Census Basic Report. Namibia Statistics Agency.

Riessman, C. K. (2008). *Narrative Methods for Human Sciences*. Los Angeles. SAGE.

Rye, H. (2001). Twelve Years of Early Intervention Studies in Ethiopia in Klein P. S. (ed.) (2001). In *Seeds of hope: Twelve Years of Early Intervention in Africa*. Oslo. Unipubforlag.

Riessman, C. K. (2008). *Narrative Methods for Human Sciences*. Los Angeles. SAGE.

Schratz, M. (Ed) (1993). *Qualitative voices in educational research*. London. The Falmer Press.

Schostak, J. (2006). *Interviewing and Representation in Qualitative Research*. Glasgow. Open university Press.

Silverman, D. (1997). Interpreting Qualitative Data: Methods for Analyzing Talk, Text and Interaction. London. SAGE.

Thody, A. (2006). *Writing and Presenting Research*. London. SAGE.