



Deafblind
International Dbl

DEAFBLIND REALITY IN AFRICA

NEW RESEARCH FROM DBI'S
AFRICAN RESEARCHERS' INITIATIVE
ARI



DEAFBLIND REALITY IN AFRICA

**NEW RESEARCH FROM DBI'S
AFRICAN RESEARCHERS' INITIATIVE ARI**

2022

Table of Contents

Introduction	4
An Analysis of Factors That Promote Transition of Learners With Deafblindness to Independent Living	5
Assistive Technology for People With Deafblindness in Southern Africa: A Delphi Study Exploring Dimensions of Impact	38
Examining the Tactile Sign Language Used by and With the Deafblind in Ethiopia	68
Management Strategies of Children With Deafblindness in Special Education Schools in Lusaka, Zambia	83
Natural Communication Abilities Among Children With Congenital Deafblindness in Multilingual Communities of Zambia	121
Specialist Andragogy for DeafBlind (DB) Interpreter Guides	141
Stimulating Research in Deafblindness in Africa	160
Towards Equitable Access to Public Information and Communication for Persons with Deafblindness in Uganda. A Case Study of COVID-19 Information	163
Visual Function Among Learners With Hearing Impairment in Schools for the Deaf in Ghana: Part 1	171



Introduction

Mirko Baur,
Vice-President Dbl

The African Researchers' Initiative (ARI) was an initiative of Deafblind International (Dbi) between 2020 and 2022.

The overall objective of ARI was to lay a strong foundation for knowledge-based services for people who are deafblind in Africa by stimulating and supporting African research on deafblindness.

ARI's specific objective was to build a network of African researchers and to support 10 outstanding research projects to be finished and ready to be presented at the 1st ever Dbi Africa Conference on Deafblindness in May 2022 in Nairobi, Kenya.

Sadly, one researcher passed away during the initiative and one stopped responding. Eight great projects, however, were finished, presented and contributed a lot to make the conference a wonderful success.

With this publication, these eight ARI research projects become widely accessible. This is undoubtedly in line with the goals of ARI and also the Africa Network newly formed at the Conference.

Dbi's Board officially recognized the Africa Network as the 16th Dbi Network on June 24, 2022. This publication is another recognition of the great work and promising potential in Africa.

The publication is also a celebration of the eight research projects and the researchers behind them. And it is a recognition of the very active coaches on ARI's Research Advisory Committee: Prof. Dr. Marleen Janssen, University of Groningen, The Netherlands; Dr. Meredith Prain, Senses Australia, Australia; Dr. Daniel Dogbe, University of Education, Winneba, Ghana; Victor Locoro, Kyambogo University, Uganda; Dr. Pawlos Kassu Abebe, Addis Ababa University, Ethiopia (Chair AC & Coordinator ARI).

Many thanks to all involved persons and organizations, enriching reading for you all and on to next Dbi research projects!

An Analysis of Factors That Promote Transition of Learners With Deafblindness to Independent Living

Dr. Everline Nyokabi and Prof. Peter Oracha,
Department of special needs education, Maseno University

Email: everlinenyokabi@gmail.com, poracha@hotmail.com

Sense International UK report (2018) has revealed that 0.2 of the world's population are deafblind and that a similar population also live with milder forms of deaf blindness. According to sense International Kenya, there are 17000 deafblind people in Kenya. Agenda 2030 and the Sustainable Development goals emphasizes the importance of leaving no one behind and ensuring quality and equity in education. Consequently, learners with deafblindness have a right to quality education that promotes independent living from early childhood to adulthood. While the general objective of educating learners with deaf blindness in Kenya is to enable them develop skills for self-reliance and independent living, a significant number are not independent. Studies have shown that learners with deafblindness are at risk of exclusion due to the relative invisibility of the disability and are unlikely to live independently. Early intervention has been found to be crucial in development of strong communication, orientation and mobility, activities of daily living, social, vocational basic literacy and numeracy skills necessary for independent living of individuals with deafblindness in the community. There is however limited research in Kenya on the preparedness of learners with deaf blindness for independent living despite the government investing heavily in their education. The purpose of this study therefore was to establish the extent of preparedness of learners with deafblindness for transition to independent living. The objectives of the study were to establish: the extent of early identification and intervention of deaf blindness; the role of parents in whole upbringing of the deafblind child; the extent to which learners with deaf blindness have acquired necessary skills for transition to independent living; and the general provisions in promoting acquisition of skills necessary for independent living of learners with deafblindness. Descriptive survey research design was adopted for this study. The study area included Baringo, Kisumu and Nairobi counties where schools for learners with deafblindness are situated in Kenya. Study population will include 38 learners with deafblindness and 35 teachers. Saturated sampling technique was used to select 33 learners with deafblindness and 25 teachers. Research instruments included questionnaire, interview schedule and document analysis guide. Qualitative data was analysed and organized into themes and sub-themes that were reported. Quantitative data will be analysed using frequency counts, per-

centages and means. The findings of this study indicated a disparity between the age of identification and admission to school. Majority (31,94.0%) of the learners were identified at the age of below 4 years but were admitted to school after 6 years of age indicating late intervention. Reports by most teachers (19,76.0%) indicated that the role of parents was mainly utility based with minimal engagement in their children's learning process. The extent of skill acquisition of learners with deaf-blindness was found to be minimal with vocational skills (Mean=1.89, and SD= 0.91) and literacy skills (Mean 1.63, SD= 0.74) being the least acquired. Majority of the teachers reported availability of basic provisions such as facilities, resource materials, human resource and government support. Limitations were however identified in provisions related to policy, curriculum differentiation, expectations on learners, teacher motivation and parental involvement. The findings of this study will inform policy of matters related to early intervention, parental involvement, transition and curriculum differentiation for learners with deaf blindness.

Introduction

The term transition describes the process in which an individual with a disability undergoes in order to move from one educational setting to another or to leave the educational system entirely and prepare for independent living and entrance into the workforce. Independent living on the other hand refers to an individual's ability to perform daily chores without support. According to Runo (2012) independent living skills are a collection of age appropriate skills necessary for leading the most self-sufficient life possible. The scope of these skills changes as an individual ages and learns new sets of skills. Quinn (2011) observed that the process of learning to be accountable for independent behaviors while functioning as part of a family,

team, group or community is a delicate balance that must begin at an early age and continue through adulthood. The skills to be given to children, youth and adults include household maintenance, use of time and money, social skills and simple meal preparation, daily living skills, community involvement, interpersonal relationship skills, job development and retention skills

Article 24 of the United Nations Convention on the Rights of Persons with Disabilities calls on nations to ensure equal access to an "inclusive, quality, and free" primary and secondary education, vocational training, adult education and lifelong learning (United Nations, 2013). The National Special Needs Education Policy Framework (2009) further envisions a society in which all persons regardless of their disabilities and special needs achieve education to realize their full potential. Special education is thus regarded as a vital tool for individuals with disabilities to realize their goals of equal opportunity, full participation in community life and economic self-sufficiency.

Today in Kenya all learners are expected to transit from primary to secondary education. The SNE Policy Review Data Collection Report (2016), however observed that transition from primary to secondary school, vocational to job placement especially for learners with severe disabilities remained a major challenge. Learners with severe, profound and multiple disabilities experienced challenges in transition com-

pared to those without and with mild and moderate disabilities (Ochieng; 2019). The Sector Policy for Learners and Trainees with Disabilities (2018) further acknowledges limited transition plans for learners with disabilities but proposes development of such plans that will guide transition of learners from primary education to the right pathways as per the competency based curriculum.

Extent of Early Identification and Intervention for Learners with Deaf Blindness

Identification of deafblindness involves recognition of deafblindness and acknowledgement of the specific support needs. However, deafblindness is still not formally acknowledged as a distinct disability in most countries today (WFDB, 2018). Furthermore, individuals with deafblindness are often not assessed by a multidisciplinary team of specialists in deafblindness with assessment methods that are suitable for the target group (Chen, Rowland, Stillman, & Mar, 2009). Consequently, the lack of knowledge on deafblindness leads to wrong diagnosis and lack of necessary services (WFDB, 2018)

Because 95 % of what one learns about the world comes through sight and hearing, challenges in communication, mobility and accessing information makes deafblindness one of the most isolating impairments and affects the whole development of the child. Identification at an early age and access to need-based early identification plays a vital role in the development of each child with deafblindness. Early intervention services for young children (aged 0-6 years) through hearing screening, visual testing, multisensory stimulation, functional visual training, speech therapy and developmental therapeutic interventions enhances the chances of reaching maximum potential for children with deafblindness significantly (Sense International India n.d.).

Experiences that occur during the earliest years of life critically impact children's abilities to learn, move, and interact with others. This is especially true for children with severe sensory and multiple disabilities, for whom physical, communicative, cognitive, social, and emotional developmental domains are deeply intertwined (Malloy et al. 2009). The early years of life are important, particularly for communication and language development, because this is the time of life when the brain is at its highest capacity to undergo structural changes in response to external stimulation, a process known as neural plasticity (Cole & Flexer, 2007). Brain research further shows that the building of organized neural systems is essential in the first year of life. The effects of either meaningful or deficient sensory experience has been found to become increasingly irreversible over time (Shonkoff & Phillips, 2000). Deficits become more pronounced with prolonged deprivation of meaningful sensory experience. Research on the plasticity of the brain related to sensory perception, including vision and hearing, confirms the critical window for timely identification of deafblindness and the provision of medical and educational intervention services (Mitchell & Maslin, 2007; Sharma, Gilley, Dorman, & Baldwin, 2007).

When deafblindness is not identified early, the child is at risk of missing medical treatment that may greatly improve health and quality of life. Further, the child may not be referred to early intervention services in a timely manner during a critical

period of early neurodevelopment. Without appropriate opportunities to learn language, children with hearing loss, including deafblindness, will likely fall behind in their communication, cognition, reading, and social- emotional development (Joint Committee on Infant Hearing, 2007).

In Kenya, Sense International launched an early intervention programme in 2017 in partnership with one hospital and three health centres. The three-year programme was piloting the first ever sensory screening and early intervention programme for children aged 0 to 3 years. The programme aimed to screen 75,000 infants for congenital impairments, provide referrals for children with single sensory impairments, and enroll children with deafblindness in early intervention services, including sensory stimulation and other therapies. Early intervention units were established within a Ministry of Health hospital and three health centres. The extent to which the early intervention services for children with disabilities have been replicated in other parts of the country is however not known hence the need for this study.

In addition, The Educational Assessment and Resource Centers (EARCs) have been set up for early identification, assessment, intervention and placement of children with special needs including the deaf blind. EARC's main objective is to equalize education opportunities for children with special needs and facilitate their full integration into the school system and their community. This approach includes early identification of children with special education needs, sensitization, counseling and training of children with disabilities and their families, parents, teachers, local administration and others in meeting the special needs of these children. Currently there are 200 operational EARC's in Kenya (Bii & Taylor, 2013). The extent to which the EARCs have promoted early identification and intervention of learners with deafblindness is however not known.

Role of Parents in the General Upbringing of a Deafblind Child

The role of a parent in a learner's education is often thought to include actions such as reinforcing learning that occurred in school, emphasizing the value of education, modeling appropriate school behaviors and attitudes, and participating in the student's instruction by assisting with homework and providing additional learning opportunities (Hoover-Dempsey & Sandler, 2005). Mukuna and Indoshi (2012) identified the roles of parents as either academic related or utility related. The academic related include helping children with reading and homework activities and providing learning materials. Utility related include paying school fees, providing physical facilities and providing feeding programs for the children and participation in its preparation. Other roles for the parents that included provision of feeding programmes for the children and participation in its preparation, ensuring better health and nutrition of their children and taking them to and from school.

Research has shown that parental participation in the education of their children plays a key role in their academic performance and general development (Emerson, Fear, Fox & Sanders, 2012). Higher levels of parent involvement are consistently associated with positive outcomes such as greater academic success (Chen & Gregory, 2009; Froiland, Peterson & Davison, 2012; Jeynes, 2007). In addition, parents are the

major socializing agent for their children as they transmit cultural values, beliefs and tradition. They also know their children better than teachers or clinicians, thus they are a source of information available from no one else. Children with disabilities have been found to acquire developmental skills more quickly when parents learn to participate in home teaching. When parents are involved in intervention program of their children they access support from other parents making them develop better perspective on their own child's strength and needs (Eileen & Ilene, 2007). Research has indicated that parental participation in the education of their children plays a key role in their academic performance and general development (Emerson, Fear, Fox & Sanders, 2012). Higher levels of parent involvement are consistently associated with positive outcomes such as greater academic success (Chen & Gregory, 2009; Froiland, Peterson, & Davison, 2012; Jeynes, 2007)

The barriers for those living with a disability and their parents are both physical and psycho-social. According to the State of Disabled People's Rights in Kenya Report (African Union of the Blind, 2007), the lives of people with disabilities in Kenya are marked by experiences of discrimination, prejudice and inequality. For children with disabilities, the obstacles include stigma which is still attached to disability, a lack of suitable transport to enable all children to make the journey each morning to the classroom, lack of appropriate technology and assistive devices to enable access to the curriculum, and a continued lack of resources, including adequately trained teaching staff. Early identification for learners with disabilities is still a challenge as most parents seek help as the last recourse. (African Union of the Blind, 2007). Other studies have shown that parental participation is related to socioeconomic status, that is, the environment in which parents and children live, their income levels, working conditions and cultural factors. All these, dictates how much time is available to parents and so their contribution to their children's education (Marpathia et. al, 2010). For children with deafblindness in African countries, primary caregivers may become immobilized by the around the clock care that they have to provide to their children. This may negatively affect their own health. The role of caregivers is increased according to the capabilities of the child. Children with severe developmental disabilities are often not brought for assessment because the parents have lost hope and some prefer to just hide the child in the house.

The Basic Education Act (Republic of Kenya, 2010). Articles 30 and 31 of this act spell out the duty of the parent or guardian of a person with a disability thus "every parent shall ensure their child attends public school which offers free and compulsory education" (Republic of Kenya 2013). The role of parents in a child's education as an integral component to the curriculum's successful implementation is further emphasized by Kenya Institute of Curriculum Development (Republic of Kenya, 2016). Specifically, the roles of parents include: (1) Providing basic necessities (2) Protecting the child from physical and emotional harm. (3) Instilling and nurture morals and values. (4) Teach and guide children to make the right choices and make them aware of consequences (5) Teaching and modelling proper use of resources (7) Instilling a sense of responsibility by ensuring children participate in age appropriate chores. (8) Helping in enhancing learning achievements in the child as guided by the teacher (9) Engaging with the teacher to enrich the child's learning experiences (10) Providing tender, loving care to boost your child's emotional safety and a sense of belonging

(11) Monitoring your child's growth and development and also identify any signs of disability for early intervention (12) Identifying the child's natural talents and abilities, and work with the teachers to nurture them (13) Discussing observed character, behavior and indiscipline issues regarding the child with teachers and taking necessary action (14) Engaging in peaceful and prompt resolution of conflicts that may arise (15) Get involved in planning, development and decision making process of school activities (16) Taking part in school activities such as academic clinics, talent

General Provisions that Promote Acquisition of Necessary Skills for Transition

The effects of combined visual and hearing impairments result to difficulties in mobility, access to information, mobility and orientation. Educational provision for learners with deafblindness should therefore provide an opportunity for them to learn and practice how to communicate, mobilise, and access information.

According to The Individuals with Disabilities Education Improvement Act (IDEA) the preparation of learners with disabilities for transition involves a set of coordinated set of activities that focus on improving the academic and functional achievement of the child. Instruction and provision of related services to the learners should therefore take into account the individual needs including strengths, preferences, and interests in acquisition of daily living, functional and vocation skills. Teachers can support learners with deafblindness by considering learners' perspectives and providing meaningful rationales for learning activities, presenting relevant learning activities, providing optimal challenges, highlighting meaningful learning goals, and supporting students' unforced endorsement of classroom behaviors (Reeve, Jang, Carrell, Jeon, & Barch, 2004). Teachers of the deafblind are expected to embrace teacher-student interactions that support students' needs for competence. This is dependent on the teachers' skills and sensitivity to individual learner needs. Unfortunately, research has shown that most teachers have difficulty with the competencies required to understand these children's experiences and emotions and connect with them in a meaningful way (Janssen, Riksen-Walraven & Van Dijk, 2002).

Managa and Masuku (2020) observed that children with deafblindness have the right to access teachers who have specific knowledge and training on deafblindness and also to information and resources specific to their needs. Their training needs should focus on the following areas: knowledge on deafblindness, skills development on managing children with deafblindness and communication strategies for the deafblind with consideration of individual cultural and linguistic characteristics of the learner. In addition, provision of constant support to educators of deafblind students would also ease the external challenges negatively affecting their role. A study by Costa (2014) however established that teachers' training and experiences were positively and significantly related to the level of support provided to deafblind learners. The study however found out that teachers were not well trained and experienced in supporting deafblind learners.

Current findings support the narrative that educators, assistant educators and staff working in schools for learners with deafblindness are not adequately equipped with the necessary skills and knowledge to teach and care for children with deafblind-

ness. These impact the teaching, guidance and communication support that they provide to the children with deafblindness (DeSimone & Parmar, 2006; Maccini & Gagnon, 2006). The lack of training on deafblindness results in teachers believing that they are not adequately prepared to instruct learners with deafblindness (DeSimone & Parmar, 2006), which is often frustrating for them. Teachers find themselves in situations where they have to take on the task of teaching, caring and supporting these children, regardless of the lack of preparedness; consequently, they resort to educating themselves on deafblindness (Gendreau, 2011).

According to Omugar (2016) whilst diversity is acknowledged and appreciated, it however presents challenges for educators of deafblind children, especially in a boarding school facility. Omugar (2016) asserts that much of the work of educators of deafblind teachers is mired by exterior influences. Factors such as different family, social, cultural environments and varied moods of the students make it difficult for educators to cope with their levels of sign language and communication needs. It is a well-known fact that in special educational contexts, children often vary in terms of age, which makes it difficult for teachers to cope with specifically knowing how to deal with deafblind learners going through adolescence. Therefore, if teachers lack the necessary knowledge, skills and resources, they will not be able to fulfil the necessary roles in adequately supporting children with deafblindness

Chimedza and Peters (2001) recommended a teacher to one learner ratio in cases of special units especially for children with severe disabilities such as those with deafblindness. This is because teachers may not have the time or resources to support all the learners with disabilities and also manage to handle their individual needs. Teacher aids are key in supporting the teacher in classroom work and this also remains a gap.

According to Runo (2012) effective transition to independent living for individuals with disabilities requires individualized planning; systematic vocational assessment and vocational skills training; academic remediation where necessary as determined by the disability and the individual: coordination and collaboration with employers. In addition, stakeholders such as special educators, guidance counselors, vocational evaluators, employers, vocational educators, parents, learners and vocational rehabilitation counselors should be involved.

Existing literature on educational support for children and young people with deaf blindness recommends the following: a) Availability of resources in appropriate formats that allow multiple means of access (visual, auditory, tactile), multiple ways of engaging with materials, and multiple routes of output (e.g. text, photograph or video) b) An appropriate environment, which includes: lighting, labelling, hearing technology such as loop systems, and safety in terms of independent mobility. c) An environment where staff and peers frequently use the same communication methods as the deafblind learner, e.g. sign, symbol or speech d) A recognition of the learner as they see themselves while ensuring that their needs are met e) Additional time for completion of tasks facilitation of social relationships f) Professionals working together in decision making and g) Training for all staff in preparing the learner to

be independent, to socialize, and to learn (Hodges, Douglas; Hewett,; McLinden, Terlektsi, Wootten, Ware, Williams, 2019)

The Kenya Ministry of Education Sector Policy for Learners and Trainees with Disabilities (May 2018) recognizes 17 policy provision for persons with disabilities. Among them are assessment and early intervention ; access to quality and relevant education and training; quality learning environment, health and safety; barrier-free environments; specialized learning resources; assistive devices and technology ; capacity building for all staff who provide and support education and training to learners and trainees with disabilities; and recruitment and re-deployment of staff to ensure that skills, qualifications, competencies and attitudes are well aligned to support learners and trainees with disabilities. This provides a basis of the necessary provisions that should be in place in educating learners with deaf blindness.

Extent of Acquisition of Necessary Skills for Transition

Appropriate education for students with disabilities must be implemented according to individual needs and to the functional skills demands of adulthood. Functional skills are those an adult needs to perform successfully in a variety of community settings. Functional living skills must be taught directly and systematically to some students with learning problems, or otherwise the students may never acquire these essential skills or may learn them through trial and error, which is both costly and time-consuming. (Runo,2012). Brolin (1993) quoted in Mercer & Mercer (2001) provides the following competencies in daily living skills: Managing personal finance; selecting and managing a household; caring for personal needs: buying, preparing, and consuming food; appropriate use of clothing; exhibiting responsible citizenship; engaging in use of recreational facilities; demonstrating knowledge of available community resources; and involvement in the community affairs. Pattoni and Kimii (2016) further emphasise of teaching life skills within the curriculum; development self-determination/ self-advocacy skills; instruction on knowledge and skills needed for adult living and Provide community-based experiences when preparing learner for transition.

A review of global deafblind literature demonstrated that persons with deafblindness, regardless of the nature of their impairment, experience significant challenges in participation in day-to-day lives especially in communication, mobility and social interactions and are at high risk of developing mental health issues as their age advances. Studies identified activities of daily living such as reading, cooking, dressing, walking in the community, shopping, attending social events, getting to a doctor's appointment, accessing information via telephone, and answering machines, as those activities where persons with deafblindness experienced challenges on regular basis. These findings allude to the need for adequate acquisition of necessary skills by learners with deafblindness for independent living skills in preparation for transition to adulthood (Jaiswal, Aldersey, Wittich, Mirza & Finlayson,2018).

In Kenya, before transition, a learner with deaf blindness is expected to have acquired numeracy and literacy skills: orientation and mobility skills; adaptive skills for living; social skills; communication skills; positive attitude towards the world

of work; physical fitness and personal talents; and vocational skills that will enable them to participate in income generating activities (Kenya Institute of Curriculum Development (KICD), 2013). Research on the extent to which the learners have acquired these skills in preparation for transition to independent living is however still minimal hence the need for this study.

Methodology

Research Design

Descriptive survey research design was adopted for this study. Descriptive research design is used to gather information on the nature or condition of a present situation. Past events and how they relate to current conditions are also considered (Cresswell, 2009; Best & Kahn, 2006). The use of the design is advantageous in that a combination of procedures such as questionnaires, interviews and observations are employed providing an opportunity for triangulation (Cohen, Manion & Morison, 2000; Kombo & Tromp, 2006). The use of descriptive survey in this study enabled the researcher to find out facts; seek opinion; describe, analyse and interpret data on factors that promote transition of learners with deafblindness to independent living.

Study Population and Sample

The study was carried out in one schools and one two units for the deafblind in Kenya located Baringo, Kisumu and Nairobi counties in Kenya. The study population comprised 38 learners with deafblindness and 35 teachers. Saturated sampling technique was used to select 33 learners with deafblindness and 25 teachers. Saturated sampling a non-probability sampling technique in which all the members of the target population are selected because they are too few select a sample out of them (Mugenda & Mugenda, 2003) In this study, teachers and learners with deafblindness were too few to necessitate picking a sample out of them.

Research Instruments

Research instruments for this study included questionnaire for teachers and interview schedule for teachers and parents. Questionnaire was considered for this study because of the ability to collect more information within a short time. Additionally, it was found to be appropriate in provision of firsthand information by teachers which could not be provided by the learners due the nature of their disability.

In-depth interviews on the other hand allowed collection of detailed information from teachers and parents on the extent early identification and intervention; role of parents; provisions that promote transition of learners with deafbliness to adulthood; and acquisition of required skills that facilitate transition by deafblind learners to the next level.

Validity and Reliability

Validity refers to the degree to which results obtained from analysis of data actually represent the phenomenon under study (Mugenda & Mugenda, 2003). In this study, face and content validity was considered. Face validity is a qualitative means of ascertaining whether a measure on the face of it appears to reflect the content of a concept (Bryman & Bell, 2003). Content validity, on the other hand, is a qualitative means of ensuring that a measure includes an adequate and representative set of items to cover a concept (Drost, 2011). The research instruments for this study were presented to experts at the department of Special Needs Education who judged the face and content validity of the instruments independently and made recommendations. Necessary adjustments were then have made based on their recommendations before the instruments are administered in the field.

Reliability refers to the extent to which a research instrument measures whatever it is meant to measure consistently (Best & Kahn, 2006). The reliability of the research instruments in this study were established through a pilot study involving 10 teachers and 5 learners did not take part in the actual study. Any inadequacies, inconsistencies and weaknesses of the research instruments identified during the pilot study will be corrected.

Methods of Data Analysis

Quantitative data collected from observation schedule was analysed using descriptive statistics such as means, frequency counts and percentages. Qualitative data collected from open-ended questions, was analysed and organised in an ongoing process according to emerging themes, sub-themes, categories and sub-categories.

A rating scale was used in establishing the extent to which learners with deaf blindness had acquired necessary skills for transition. The score values were assigned as follows: Very Large Extent (VLE) = 5 points, Large Extent (LE) = 4 points, Small Extent (SE) = 3 points, Very Small Extent (VST) = 2 points and Not Yet Acquired (NA) = 1 point. Skill acquisition mean score of 2.99 and below was interpreted as very small extent, between 3.0 and 3.99 as small extent and 4 and above as large extent.

Results

The study aimed at establishing the extent of early identification and intervention of deaf blindness; the role of parents in whole upbringing of the deafblind child; extent to which learners with deaf blindness have acquired necessary skills for transition to independent living; and the general provisions in promoting acquisition of skills necessary for independent living of learners with deafblindness.

Demographic characteristics

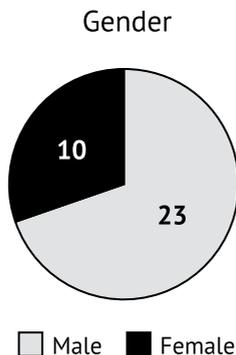


Fig. 1: Distribution of learners with deafblindness according to gender.

As illustrated in Figure 1, 23 (69.7%) male learners and 10(30.3%) females participated in the study. The number of male learners was more than that of females

Cause of Deaf blindness

The cause of deafblindness for most learners (26, 78.8%) with deaf blindness deaf-blindness was unknown, followed by German measles at 3 (9.1%) and premature birth was least with 2(6.1%).

Severity

Table 1 shows level of Severity of deafblindness for the learners who participated in the study

Table 1: Severity levels of Deafblindness

Level of Severity	f(%)
Mild	7(21.21)
Moderate	5(15.15)
Severe	21(63.64)
Total	33(100%)

From the Table 1 majority of the learners (21, 63.64%) had severe deafblindness.

Age

Table 2: Age of learners with Deafblindness

Age	f(%)
10 years and below	6(18.18)
11- 15 years	15(45.45)
16-20 years	11(33.33)
Above 20 years	1(3.03)
Total	33(100%)

Table 3 shows the age of learners who participated in this study. From the table most learners were teenagers with a majority (15, 45.45%) being 11-15 years old. The mean age of deaf blind learners was 14.21 with the youngest learner aged learner being 7yrs and the oldest 21 years,

Extent of Early Identification and Intervention for Learners with Deaf Blindness

The extent of early identification and intervention for learners with deaf blindness was established through document analysis and teacher interviews. Tables 1 and 2 show data on the age of identification and age of admission to school of learners with deaf blindness respectively.

Table 3: Age of Identification

Age	Frequency (f)	Percentage (%)
Below 4 years	31	94
4-6 Years	1	3
After 6 years	1	3
Total	33	100

Table 4: Age of Admission to School

Age	Frequency (f)	Percentage (%)
Below 4 years	2	6.0
4-6 Years	12	36.4
After 6 years	19	57.6
Total	33	100

Tables 3 and 4 show disparity in terms of age of identification and admission to school with most learners joining school at the age over six years. This has implications on language acquisition since the learners are past the critical age of language acquisition. Language and cognition are related, there is therefore a likelihood of the learners lagging behind in cognitive development and other developmental milestones.

The disparity can be associated with the social-economic status of the parent where most were found to be farmers (22, 66.7%) and stigma. Early intervention ameliorates the impact of disability on a child in terms of early acquisition of skills and developmental milestones.

General provisions in promoting acquisition of skills necessary for independent living of learners with deafblindness

Responses from teachers indicated that the general provisions for acquisition of skills necessary for independent living of learners with deafblindness in respective schools were: Learning materials and facilities; support from government and well-wishers; human resources; and parental empowerment as evidenced by the following responses

Teacher 15:

“We have facilities in terms of classroom space, teaching and learning resources that are used to facilitate learning of various skills in various learning areas of the curriculum design to equip the learner with the necessary knowledge skills and attitude.”

Teacher 4:

“One of the provisions that we have in our school is empowering the parents through necessary support and training to be advocates of their children with deafblindness.”

Teacher 22:

"The school has some support from the government and well-wishers though not in transition."

Reports from teachers indicate that basic provisions for learning were in place in schools for the deafblind. However specific provisions in terms curriculum differentiation were not expressed. Carrell, Jeon and Barch, (2004) identified some of the provisions related to learning as; presenting relevant learning activities, providing optimal challenges, highlighting meaningful learning and supporting classroom behaviors. Janssen, Riksen- Walraven, and Van Dijk(2002), further emphasized that teachers of the deafblind are expected to embrace teacher-student interactions that support students' needs for competence. experiences and emotions and connect with them in a meaningful way

Teachers however reported challenges related to the general provisions including; inadequate resources; payment of school fees and provision of basic necessities by parents; involvement of parents in reinforcing acquired skills; learners taking too long to acquire skills; lack of consistency due to learner absenteeism; Curriculum limitations in terms of relevant skills for learners with deafblindness. This is evidenced by the following responses:

Teacher 3

"It takes so many years for the children to learn a skills and other do not even acquire the skills desired "

Teacher 9

"The curriculum has been amalgamated with some other severe cases of disabilities which does not to a great extent support the unique needs of these categories of learners."

Teacher 11

"Where there is no formal assessment of learners, there tends to be a negligence and under expectation especially by parents on learners' acquisition of skills"

Teacher 25

"Opportunities for upward mobility in terms of promotion are limited for teachers of learners with deafblindness since there are no mean scores to show as evidence hence low motivation among teachers"

Teacher 15

"Limited expertise in the area of Deaf blindness at the Ministry of Education and TSC has led to ineffective policy formulation e.g. On pupil- teacher ratio for learners with unique and varied need like the deafblind."

In terms of expectations on their children, most parents had very low expectations in terms of skill acquisition and capabilities of their children which was limited to activities of daily living.

This is evidenced by the following responses:

Parent 8

"He can feed himself, move around, but not toileting"

Parent 1

My child can play, feed but can't bath or dress

Parent 7

"She can do washing, bathing, sweeping, slashing and toileting but cannot dig"

Parent 3

"My son can toilet, feed, dress, sweep, likes arranging things, likes beadwork and painting, though not able to cook or wash"

Role of parents in promoting transition of learners with Deafblindness to independent living

The study sought to establish the role of parents in promoting transition of learners with deafblindness to independent living. Involvement of parents in the education of their children has been found to have positive impact in terms of learners' academic achievement. Parents act collaborators with teachers in ensuring that skills learnt in schools are also emphasized at home

Data on role of parents was collected through teacher and parent interviews. According to teachers the role of parents in their school included provision of basic needs to the learner, providing information regarding their children and paying school fees. Collaboration with the school in enhancing skill development of learners with deaf blindness was only mentioned by one teacher 1(4.0%). This indicated that most teachers perceived the role of parents as material provision with minimal expectation in terms of participation in their children's learning process. This was further supported by 19(76.0%) of the teachers who indicated that the extent of parental participation in the learning of deafblind children was minimal.

On the other hand, parents reported their roles as provision of school fees, shopping and transport as evidenced by reponses from parent 2 and 8:

Parent 2:

"I do my work as a parent by paying school- fees, shopping for basics and home basics "

Parent 8

"I pay school fees and do shopping for my child. At home I ensure that my child eats well, you know these special children need special diet"

One parent however reported that they supported their child in learning skills as per the following remarks:

Parent 7

“I support him with learning skills and achieving milestones, provide playing toys used for his learning and follow the occupational therapist guidance, both in school and at home.”

Reports from teachers and parents indicate that the role played of parents of learners with deafblindness is largely material based. This finding concurs with one of the roles cited in the Competence Based Curriculum (2016) and Mukuna and Indoshi (2012) who in their study identified the role of parents as utility related. Provision of basic necessities is however one among many of the roles of parents stipulated by the Competence Based Curriculum. Evidence from this study however indicates that the role of the parents in terms of engagement in the learning process is yet to be acknowledged by parents of learners with deaf blindness. Minimal engagement of parents in the learning process of deaf blind learners therefore implies limited skill acquisition which negatively affects their transition to independent living.

Extent of Acquisition Skills of Necessary for Transition to Independent Living

The study aimed at establishing the extent to which learners with deafblindness had acquired necessary skills for transition to independent living. The skills considered for the study included daily living skills, Orientation and mobility skills, communication skills, literacy skills, vocational and social skills. Data collected through teacher questionnaires and results presented in Table 5,6,7,8,9,10 and 11.

Table 5: Extent of Acquisition of Skills Necessary for Transition to Independent Living

Age	Mean	Standard Deviation
Daily Living Skills	2.73	0.93
Orientation and Mobility Skills	3.30	0.94
Communication Skills	2.76	0.87
Literacy Skills	1.63	0.74
Vocational skills	1.89	0.91
Social skills	2.64	1.03

Table 5 shows extent of acquisition of skills necessary for transition to independent living by learners with deaf blindness. From the table acquisition of orientation and mobility skills was to small extent (Mean = 3.30, SD=0.94). The skills that had been acquired to a very small extent included daily Living skills (Mean=2.73, SD=0.93), communication skills (mean= 2.76, SD=0.87) and social skills (Mean= 2.64, SD=1.03). The kills that were yet to acquired included vocational skills (Mean=1.89) and literacy skills (Mean= 1.63, 0.74). It can therefore be deduced that extent of skill acquisition among learners with deaf blindness is minimal.

The ability of learners with deafness to fairly move from one place can be attributed to the frequency in which the learners move from one place to another in performing daily activities. However, the extent of acquisition would be considered as inadequate to enable a learner with deaf blindness to function independently. This implies that upon transition a learner who is deafblind may not be aware of where they are or where they want to go. In addition, they will experience challenges in moving safely, efficiently, and effectively within their environment.

Low level acquisition of vocational skills limits the opportunities for learners with deaf blindness upon transition in terms of further skill development, job opportunities, independence in life and becoming productive members in the in the society. Low literacy skills on the other hand hinder that learners with deaf from communication, access to information, entertainment, financial negotiations, identifying things and places which ultimately results to dependence and inclusion in the society.

The study further established extent of acquisition of independent components of the skills. The data is presented in Tables 6, 7, 8, 9, 10 and 11.

Table 6: Extent of Acquisition of Daily Living Skills(n=33)

Skill	Mean	Standard Deviation
Dressing	3.00	1.173
Personal Hygiene	3.27	1.281
Feeding	3.55	1.325
Household Chores	2.85	1.278
Toileting	3.09	1.100
Identification of personal effects	2.73	1.353
Maintaining cleanliness	2.70	1.287

Skill	Mean	Standard Deviation
First Aid	1.97	1.159
Menstrual Hygiene	1.33	0.645
Routine	2.85	1.253
Overall Mean	2.7333	0.93330

Table 6 shows the extent of acquisition of daily living skills by learners with. From the table the skills that had been acquired to a small extent were feeding (Mean = 3.27, SD= 1.33) and personal hygiene (Mean=3.27,SD=1.28). The skill that was not yet acquired was menstrual hygiene (Mean=1.33,SD=0.65). Feeding and personal hygiene are among most necessary basic skills that a child is expected to acquire for survival. The acquisition of the skills by the learners to a small extent can be attributed to the frequency in which feeding and personal hygiene activities occur daily, importance of the skills and the emphasis given to acquisition of the skills.

The minimal acquisition of menstrual hygiene skills can be attributed to the fact that majority of the learners who participated in the study were males hence acquisition of the skill did not apply to them.

Inadequate acquisition of daily living skills implies that learners with deafblindness lack essential skills for survival in the community. This ultimately hinders their ability to be independent, responsible and have quality lives.

Table 7: Extent of Acquisition of Orientation and Mobility Skills (n=33)

Skill	Mean	Standard Deviation
Maintaining appropriate posture and balance	3.61	1.223
Use mobility devices	2.73	1.464
Moving safely within the environment	3.64	1.113
Location of Objects within the environment	3.31	1.256
Location of place within the environment	3.42	1.146

Skill	Mean	Standard Deviation
use of body parts to explore the environment	3.48	1.176
Use of body parts to function the environment	3.30	1.212
Determining position in space and direction of movement	3.30	1.212
Carrying items from one place to another	3.42	1.300
Use of public amenities	2.82	1.334
Overall Mean	3.3091	0.94418

Table 7 shows data on the extent of acquisition of orientation and mobility skills by learners with deaf blindness. From the table the extent of acquisition of orientation and mobility was to a small extent (Mean= 3.31, SD= 0.94). The sub-skills that had been acquired to a small extent were maintaining posture and balance (Mean=3.61, SD=1.22) and moving safely within the environment (Mean=3.64, SD=1.1). The skills that were acquired to a very small extent include use of public amenities (Mean= 2.82, SD= 1.33) and use of mobility aids (Mean=2.73, SD=1.47). It can therefore be deduced that the extent of acquisition of orientation and mobility skills by learners with deaf blindness was inadequate.

Orientation and mobility skills enable an individual to move from one place to another. For learners with deafblindness effective orientation and mobility skills allow them to explore the environment, communicate, collect information and make choices. Good posture and balance and ability to move safely within the environment ensures stability, confidence, independence and provides a sense of security while exploring the environment. Inadequate skills in orientation and mobility in learners with deafblindness therefore point to dependence, low productivity, limited world knowledge, learned helplessness and fear. These limitations eventually hinder effective transition of learners with deafness to independent living.

Table 8: Extent of Acquisition of Communication Skills (n=33)

Skill	Mean	Standard Deviation
Expressive communication skills	2.85	1.004
Receptive communication skills	3.03	0.951
Establishing and sustaining attention	3.06	1.029
Use of appropriate augmentative communication and alternative communication	2.55	1.063
Names and function of objects	2.39	1.029
Communications with partners	2.64	1.141
Identifications of individuals	2.82	1.103
Communication in various domain	2.82	1.044
Use of alternative communication skills	2.88	1.111
Turn taking in communication	2.58	1.226
Overall Mean	2.7606	0.86960

Table 8 shows data on the extent of acquisition of communication skills by learners with deafblindness. From the table the extent of acquisition of communication skills was to a very small extent (Mean=2.76, SD= 0.87). Communication skills that had been acquired to a very small extent were receptive communication skills (Mean= 3.03, SD=0.95) and establishing and sustaining attention (Mean=3.06, SD= 1.03).

Communication skills that had been least acquired were names and functions of objects (Mean= 2.39, SD= 1.03) and use of augmentative and alternative communication (Mean=2.55, SD=1.063). It can therefore be concluded that acquisition of communication skills by learners with deafblindness was to a very small extent.

Inability to name objects and their functions in the environment implies that learners with deafblindness will experience challenges in carrying out basic meaningful conversations, interacting and using common objects within their environment. Lack of alternative ways of communication on the other hand may lead to frustration due to the inability to express oneself; needs not being addressed and misunderstanding with communication partners. In general, limited communication skills put learners with deafblindness at risk of exclusion, access to information, social interaction and making informed decision making in life.

Table 9: Extent of Acquisition of Literacy Skills (n=33)

Skill	Mean	Standard Deviation
Pre-reading	1.79	0.781
Pre- writing skills	1.82	0.846
Identification and articulation of letters of the alphabet	1.73	0.944
Identification and articulation of numbers	1.67	0.854
Vocabulary Acquisition	1.64	0.895
Writing shopping list	1.39	0.788
Mathematical Operations	1.45	0.905
Measurement	1.61	0.966
Money	1.64	0.895
Entrepreneurial skills	1.58	1.032
Overall Mean	1.6303	0.73971

Table 9 shows data on the extent of acquisition of literacy skill by learners with deaf-blindness. From the table the extent of acquisition of literacy skills is generally to a very small extent (Mean=1.64, SD= 0.74) with writing a shopping list (Mean=1.39, SD= 0.79) and Mathematical operations being (Mean= 1.45, SD= 0.91) being the least acquired. It can therefore be concluded that acquisition of literacy skills among learners with deafblindness was very low.

The need for numeracy skills with the rapid advancement in technology cannot be ignored. Use of simple but necessary digital gadgets such as mobile phone for communication requires numeracy skills. Numeracy skills are critical in everyday activities such as solving problems; making sense of time, planning for meals, cooking, interpreting receipts and prescriptions, budgeting for shopping or even playing a sport. At the work place arriving on time, scheduling and meeting deadlines requires numeracy skills. Inadequate numeracy skills therefore limit the independence of learners with deaf blindness in terms of communication, employability, scheduling, shopping and leisure.

Table 10: Extent of Acquisition of Vocational Skills (n=33)

Skill	Mean	Standard Deviation
Laundry	2.36	1.220
Beadwork	2.55	1.416
Gardening	1.94	1.248
Animal Farming	2.06	1.171
Weaving and Basketry	1.79	1.053
Knitting	1.58	0.792
Woodwork	1.64	0.822
Cookery	1.64	0.962
Beauty therapy	1.61	0.864
Overall Mean	1.8879	0.90718

Table 10 shows extent of acquisition of vocational skills by learners with deaf blindness. From the vocational skills that were acquired to a very small extent were beadwork (Mean=2.55, SD=1.416) and laundry (Mean=2.36, SD=1.416). The skills that were yet to be acquired included beauty therapy (Mean= 1.61, SD=0.864).

Beading is a popular activity that is enjoyed by people of all ages especially for leisure. Acquisition of the skill can be considered as less tedious, fun, easy to teach and learn. Engagement of the learner mentally and physically in the task provides them with freedom of self-expression and a sense of accomplishment upon completion of a task. The acquisition of the skill therefore can be associated with the fact that beading may be less tiresome compared to gardening or cooking hence appropriate for learners with deaf blindness. It is easy to teach and materials are affordable. The likelihood prioritizing acquisition of the skill is therefore.

Laundry is a skill that involves several component skills making it complex. Laundry as an activity is also tedious. Learners with deaf blindness may not readily or easily acquire the skill. Teaching the skill to the learners is equally challenging. Inability to carry out basic daily chores such as laundry is a hindrance to transition to independent living.

Limited acquisition of beauty therapy skills can be associated with the fact that most schools did not have adequate resources for teaching beauty therapy and the fact that the skill was not taught in some schools.

Table 11: Extent of Acquisition of Social Skills (n=33)

Skill	Mean	Standard Deviation
Participation in games and sports	2.97	1.045
Participation in music and dance	2.91	1.042
Building interpersonal relationships	2.79	1.219
Cooperation with others	2.88	1.244
Initiating Conversation	2.56	1.366
Participating and maintaining conversation with others	2.30	1.425
Problem solving	2.45	1.121
Self-management	2.48	1.253

Skill	Mean	Standard Deviation
Having preference and choices	2.64	1.342
Etiquette	2.39	1.059
Overall mean	2.6364	1.03163

Table 11 shows the extent of acquisition of social skills by learners with deafblindness. The skills that were acquired to a very small extent included participation in games and sports (Mean=2.97, SD= 1.04) and participation in music and dance (Mean= 2.91, Mean=1.04). The least acquired social skill was participating and maintaining conversations with others (Mean=2.30, SD=1.42).

Sports, games, music and dance naturally evoke a sense of enjoyment and fun. They allow interaction, communication, cooperation, release of energy, realization of full potential and development of independence. The enable the learners to become physically and mentally strong. The acquisition of the skill to a very small extent can be associated with the fun and enjoyment that comes with them. Engagement in sports, games and dance therefore tends to be less demanding and learners are likely to readily and frequently engage in them.

Limited skills in participating and maintaining conversations among learners with deafblindness can be associated with lack of communication skills, language, partners, topics and motivation. This puts them at risk isolation and depression upon transition.

Conclusions

The findings of this study indicated a disparity between the age of identification and admission to school. Majority of the learners were identified at the age of below 4 years but were admitted to school after 6 years of age indicating late intervention. The role of parents was found to be mainly utility based with minimal engagement in their children's learning process. The extent of skill acquisition of learners with deafblindness was found be minimal with vocational skills and literacy skills being the least acquired. Provision in terms of resources was found to be available but inadequate. Further limitations were identified in provisions related to policy, curriculum differentiation, expectations on learners, teacher motivation and parental involvement.

Recommendations

In light of the findings of this study and suggestions from teachers, this study recommends the following:

1. Involvement of teachers of the deafblind in designing of the curriculum. This will ensure inclusion of relevant skills and learning experiences for learners with deafblindness.
2. Organizing seminars and workshops for parents to empower them in supporting their deafblind children's education and eventual transition
3. Collaboration of schools with potential employers in securing opportunities and ensure smooth transition of learners with deafblindness
4. Provision of quality human and material resources by the government for effective skill acquisition by learners with deafblindness.
5. Strengthening policies related to early identification and transition of learners with deafblindness .
6. Considering relevant indicators of performance for teachers of learners with deafblindness in promotion. This will ensure career progression and motivation among the teachers of the deafblind

References

- African Union of the Blind (AFUB). 2007. In Collaboration with Kenya Union of the Blind. 2007. *"State of Disabled Peoples Rights in Kenya."* Nairobi: African Union of the Blind
- Best, W. J., & Kahn, V. J. (2006). *Research in Education* (10th ed.). New Delhi: Prentice-Hall.
- Bii, C., & Taylor, L. (2013). *Inclusive education in Kenya Assessment report*. Kenya/Somalia Program. Handicap International. Policy Paper on Inclusive Education.
- Bryman, A., & Bell, E. (2003). *Business research methods*. UK: Oxford University Press.
- Emerson, L., Fear, J., Fox, S., and Sanders, E. (2012). *Parental engagement in learning and schooling: Lessons from research*. A report by the Australian Research Alliance for Children and Youth (ARACY) for the Family-School and Community Partnerships Bureau: Canberra.
- Chen, W., & Gregory, A. (2009). Parental involvement as a protective factor during the transition to high school. *Journal of Educational Research*, 103, 53–62.
- Chen, D., Rowland, C., Stillman, R., Mar, H. (2009). Authentic practices for assessing communication skills of young children with sensory impairments and multiple disabilities. *Early Childhood Services: An Interdisciplinary Journal of Effectiveness*, 3, 323–338.
- Chimedza R, Peters S. (2001). *Disability and special educational needs in an African context*. Harare, College Press.

- Cohen, L., Manion, L., & Morrison, K. P. B. (2000). *Research methods in education*. London: Croomhelm.
- Cole, E. B., & Flexer, C. (2016). *Children with hearing loss: Developing listening and talking, birth to six* (3rd ed.). Plural Publishing.
- Costa, J. C. (2014). Teacher Characteristics in Supporting Deafblind Learners: A Case of Kabarnet School for Deafblind Children, Baringo County, Kenya. *Journal of Education and Practice*
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches*. London: Sage Publications.
- DeSimone J.R., & Parmar R.S. (2006). Middle school mathematics teachers' beliefs about inclusion of students with learning disabilities. *Learning Disabilities Research & Practice*, 21(2), 98–110.
- Gendreau S. (2011). *A study of caregiver experiences in raising a deaf children*. Retrieved from <https://mspace.lib.umanitoba.ca/bitstream/handle/1993/4483/WHOLE%20THESIS%20-%20April%205-%20SANDI%20GENDREAU.pdf?sequence=1&isAllowed=y>
- Froiland, J. M., Peterson, A., & Davison, M. L. (2013). The long-term effects of early parent involvement and parent expectation in the USA. *School Psychology International*, 34, 33-50.
- Hodges, L; Ellis, L; Douglas, G; Hewett, R; McLinden, Terleksi, E; Wootten, A; M; Ware, J; Williams, L; (2019). A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with multi-sensory impairment. Cardiff: Welsh Government, GSR report number 51/2019. Available at: <https://gov.wales/effectiveness-educational-interventions-support-childrenand-young-people-multi-sensory>
- Hoover-Dempsey, K.V., Walker, J.M.T., Sandler, H.M., Whetsel, D., Green, C.L., Wilkins, A.S., & Closson, K.E. (2005). Why do parents become involved? Research findings and implications. *Elementary School Journal*, 106(2), 105-130.
- Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., & Finlayson, M. (2018). Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PLoS one*, 13(9).
- Janssen, M.J., Riksen-Walraven, J.M. & van Dijk, J.P.M. (2002). Enhancing the Quality of Interaction Between Deafblind Children and Their Educators. *Journal of Developmental and Physical Disabilities* 14, 87-109.
- Jeynes, W. (2007) The Relationship Between Parental Involvement and Urban Secondary School Student Academic Achievement: A Meta-Analysis. *Sage Journals*, 42(1) 82-110

- Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics* 120(4), 898–921.
- Kombo, K. D., & Tromp, A. L. D. (2006). *Proposal and thesis writing: An introduction*. Nairobi: Pauline Publications Africa.
- Maccini P., & Gagnon J.C. (2006). Mathematics instructional practices and assessment accommodations by secondary special and general educators. *Exceptional Children*, 72(2), 217–234.
- Malloy, P., Stremel Thomas, K., Schalock, M., Davies, S., Purvis, B., & Udell, T. (2009). Early identification of infants who are deafblind. Monmouth, OR: National Consortium on DeafBlindness
- Manga, T., & Masuku, K.P. (2020). Challenges of teaching the deafblind learner in an education setting in Johannesburg: Experiences of educators and assistant educators. *South African Journal of Communication Disorders*, 67(1), a649.
- Marphatia, A. A., Edge, K., Legault, E., & Archer, D. (2010). Politics of participation: parental support for children's learning and school governance in Burundi, Malawi, Senegal and Uganda. The Improving Learning Outcomes in Primary Schools. Institute of Education and Action Aid. http://www.actionaid.org/sites/files/actionaid/il-ops_parents_final.pdf
- Ministry of Education (2018). Sector Policy for Learners and Trainees with Disabilities. Ministry of Education
- Mitchell & Maslin (2007) How vision matters for individuals with hearing loss. *International Journal of Audiology* 2007; 46:500-511
- Mugenda, O. N., & Mugenda, A. G. (2003). *Research Methods: Quantitative and Qualitative Approaches*. Nairobi: African Center for Technology Studies Press.
- Mukuna, T. E. & Indoshi, F.C.(2012 Parental Involvement and Perceptions of Their Role in Early Childhood Development Education Pedagogy in Kenya. *International Journal of Current Research*, 4(2), 265-274
- Ochieng, F. H. & Murungi, N. Attaining 100% Transition from Primary Schools for Learners with Disabilities in Kenya: Reality or Fantasy? *Commonwealth of Learning (COL)*, 2019-09
- Omugur, J. P. & Bunyasi, B. A. (2016) Teachers' Use of Communication Techniques for Achievement of Daily Living Activities by Learners with Deafblindness in Primary Schools, Uganda. *International Journal of Education and Research*, 4(9).
- Quinn, J. 2011. *Special Needs Quarterly: Independent Living Skills*, <http://Blog.abcteach.com/archives/82>.

Reeve, J., Deci, E. L., & Ryan, R. M. (2004). Self-determination theory: A dialectical framework for understanding the sociocultural influences on student motivation. In D. M. McInerney & S. Van Etten (Eds.), *Research on sociocultural influences on motivation and learning: Big theories revisited* (Vol. 4, pp. 31-59). Greenwich, CT: Information Age Press

Republic of Kenya. (2009). *The National Special Needs Education Framework*. Nairobi: MoE.

Republic of Kenya (2010a). *The Constitution of Kenya*. Nairobi: Government Printer.

Republic of Kenya (2016). *Basic Education Curriculum Framework (BECF)*. Nairobi: Government Press.

Runo, M. (2012) Independent Living for Persons with Disabilities. *Les Cahiers d'Afrique de l'Est. The East African Review*, 46(1), 11-25.

Sharma, A., Gilley, P. M., Dorman, M., & Baldwin, R. (2007). Deprivation-induced cortical reorganization in children with cochlear implants. *International Journal of Audiology*, 46(9), 494-499.

Shonkoff, J. P., & Phillips, D. A. (Eds.). (2000). *From neurons to neighborhoods: The science of early childhood development*. National Academy Press.

World Federation of the Deafblind (2018). *At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with deafblindness*. Initial global report on situation and rights of persons with deafblindness. Oslo: World Federation of the Deafblind.

Teachers' interview schedule

We (Dr. Everline Nyokabi and Prof. Peter Oracha) are carrying out a studying a study on **an analysis of factors that promote transition of learners with deafblindness to independent living**. You have been selected as a respondent in this study because of your role in teaching and learning of deafblind learners. Based on your experience and knowledge please provide your views pertaining to the study. I assure you that the information you provide will only be used for academic purposes and will be treated with utmost confidentiality. Thank you for your anticipated participation in the study.

1. Which factors promote transition of learners with deafblindness to independent living in your school?
2. What role do parents of learners with deafblindness in your school play in promoting transition of learners with Deafblindness to Independent living?
3. What provisions do you have in your school to support teaching and eventual transition of learners with deafblindness?

4. To what extent do you receive support from parents in preparation of learners with deaf blindness for transition?
5. What challenges do you face in implementing the curriculum for learners with deafblindness?
6. What other challenges do you face in teaching learners with deafblindness?
7. What are your suggestions in promoting early identification, assessment, intervention and transition of learners with deafblindness?

Teachers' questionnaire

We (Dr. Everline Nyokabi and Prof. Peter Oracha) are carrying out a studying a study on **an analysis of factors that promote transition of learners with deafblindness to independent living**. You have been selected as a respondent in this study because of your role in teaching and learning of deafblind learners. Based on your experience and knowledge please provide your views pertaining to the study. I assure you that the information you provide will only be used for academic purposes and will be treated with utmost confidentiality. Thank you for your anticipated participation in the study.

Learners' Code						
Cause of Deafblindness						
Gender						
Age						
Category of Deaf blindness						
Severity						
Date of admission to School						
	Skill	Extent of skill acquisition (Tick where appropriate)				
		VLE (Very Large Extent)	LE (Large Extent)	SE (Small Extent)	VSE (Very Small Extent)	NYA (Not Yet Acquired)
	Daily Living Skills					
i	Dressing					
ii	Personal Hygiene and grooming					
iii	Feeding					
iv	Household chores					
v	Toileting					
vi	Identification of personal items					

vii	Maintaining cleanliness of the working areas					
viii	First Aid					
ix	Menstrual Hygiene					
x	Routines					
	Orientation and Mobility Skills					
i	Maintaining appropriate posture and balance					
ii	Use of mobility devices					
iii	Moving safely within the environment					
iv	Location of objects within the environment					
v	Location of places within the environment					
vi	Use of body parts to explore the environment					
vii	Use of body parts to function within the environment					
viii	Determining position in space and direction of movement					
ix	Carrying items from one place to another					
x	Use of public amenities					
	Communication Skills					
i.	Expressive communication skills					
ii.	Receptive communication skills					
iii	Establishing and sustaining attention					
iv.	Use of appropriate augmentative and alternative communication					
v.	Names and an functions of objects					
vi	Communication with partners					

vii	Identification of individuals through various means					
viii	Communication in various domains					
ix.	Use of alternative communication modes					
x.	Turn taking in communication					
	Literacy Skills					
i	Pre-Reading skills					
ii	Pre-Writing skills					
iii	Identification and articulation of letters of the alphabet					
iv	Identification and articulation of numbers					
v	Vocabulary Acquisition					
vi	Writing a shopping list					
vii	Mathematical operations					
viii	Measurement					
ix	Money					
x	Entrepreneurial skills					
	Vocational Skills					
i.	Laundry					
ii.	Beadwork					
iii.	Cookery					
vi.	Gardening					
v	Animal Farming					
vi	Weaving and Basketry					
vii	Knitting					
viii	Woodwork					
ix	Beauty therapy					
	Social Skills					
i.	Participation in games and sports					

ii	Participation in music and dance					
iii	Building interpersonal relationships					
iv	Cooperation with others					
v	Initiating conversations					
vi	Participating and maintaining conversations with others					
vii	Problem solving					
viii	Self-management					
ix	Having Preferences and choices					
x	Etiquette					

Document analysis guide

We (Dr. Everline Nyokabi and Prof. Peter Oracha) are carrying out a studying a study on **An analysis of factors that promote transition of learners with deafblindness to independent living**. You have been selected as a respondent in this study because of your role in teaching and learning of deafblind learners. Based on your experience and knowledge please provide your views pertaining to the study. I assure you that the information you provide will only be used for academic purposes and will be treated with utmost confidentiality. Thank you for your anticipated participation in the study.

1. Date of Birth
2. Profession of parents
3. Date of Onset of Deafblindness
4. Cause of Deafblindness
5. Category of Deafblindness
6. Severity of Deafblindness
7. Additional disabilities
8. Date of assessment
9. Date of Admission

Parents interview schedule

We (Dr. Everline Nyokabi and Prof. Peter Oracha) are carrying out a studying a study on **an analysis of factors that promote transition of learners with deafblindness to**

independent living. You have been selected as a respondent in this study because of your role as a parent of a learner with deafblindness. Based on your experience and knowledge please provide your views pertaining to the study. I assure you that the information you provide will only be used for academic purposes and will be treated with utmost confidentiality. Thank you for your anticipated participation in the study.

1. What is your profession?
2. When did your child acquire deaf blindness?
3. What caused deaf blindness to your child?
4. How did you know that your child has deafblindness?
5. What did you do after knowing that your child has deafblindness?
6. What can your child do/ not do?
7. What challenges do you experience with your child who is deaf blind?
8. How do you support your child who is deafblind at home and school?

Assistive Technology for People With Deafblindness in Southern Africa: A Delphi Study Exploring Dimensions of Impact

Diane Bell,

Faculty of Business and Management Sciences, Cape Peninsula University of Technology, Cape Town, South Africa, Business School, University of Stellenbosch, Bellville, South Africa;

Meredith Prain,

Centre of Excellence – Deafblind, Able Australia, Melbourne, Australia;

Natasha Layton,

Ageing and Independent Living Research Centre, Monash University, Melbourne, Australia.

ABSTRACT

Purpose: Assistive technology (AT) is a highly effective intervention to address the capability gap for people living with deafblindness. The My AT Outcomes Framework (MyATOF) is a novel Australian framework founded upon AT process principles and outcomes research. It guides stakeholders to articulate AT use according to 6 dimensions. MyATOF was developed as a data collection and knowledge translation tool. The use case of AT by people with deafblindness in Southern Africa was investigated in this study to determine the applicability of MyATOF dimensions to (a) people with deafblindness and (b) low- and middle-income countries.

Materials and methods: Two online surveys, using the Delphi methodology, were undertaken with key stakeholders including people with deafblindness, family members, researchers, service providers, educators and advocates. An expert panel of 17 completed Phase 1, with 14 completing Phase 2. The WHO 5Ps AT systems thinking model was used in data analysis.

Results: Respondents affirmed the validity of the dimensions of MyATOF for people with deafblindness in four Southern African countries. In-country barriers and constraints were identified as significantly impacting the capacity of AT users with deafblindness, to realize positive outcomes.

Conclusions: The MyATOF dimensions show promise in their use with persons with deafblindness in Southern Africa, though further research is needed.

IMPLICATIONS FOR REHABILITATION

- The impact of assistive technology and related supports can be evaluated across a number of dimensions including human rights, costs incurred and saved, consumer experience, and service delivery satisfaction.
- These dimensions of impact resonate across the two continents investigated to date, with contextual factors being considered.
- Variables influencing access to assistive technology across contexts can be understood through the WHO GATE five P's systems thinking model.
- Few tools place data capture and outcomes measurement in the hands of assistive technology users, but indications are that this is of value to consumers.

Introduction

People with disability experience disadvantages in socio-economic and employment status and lower overall health status [1,2]. Assistive technology (AT) is a key enabler of improved outcomes for people with disabilities, including those with deafblindness, in all life domains. However, tools are needed to assist people with disabilities to articulate needs, goals, and rights related to the use of AT, and to evaluate and measure AT-related outcomes, in order to make the case for appropriate AT provision.

Assistive technology

AT is an umbrella term for assistive products and related services, the use of which maintains or improves a person's ability to function and be independent, thus promoting their well-being [3]. When provided effectively, AT can be used to fill the capability gap between a person's functional capacity and the demands of their environments, enabling people to participate in daily life and work and to achieve the United Nations Sustainable Development Goals [4]. AT represents a hugely impactful yet under-realized intervention and a cost-effective investment for governments [5].

Assistive products include devices, equipment, instruments, and software, designed and produced especially, or available generally on the market. AT services include assessment, product fitting, training, troubleshooting and maintenance support, which are critical to the safe and effective use of products. Accordingly, AT is understood as a complex system requiring policies and markets that can deliver end-to-end products and services [6]. The application of systems thinking within the global AT community has identified five strategic drivers which are critical to realizing the full potential of AT for global citizens. Termed the "5Ps" and comprising people (that is, AT users and their social networks), policy, products, personnel, and provision, these form the basis of strategic actions by the WHO Global Access to AT (GATE) team [7]. Additional, situational factors of procurement, place, pace, promotion, and partnership have been hypothesized as other critical factors influencing AT outcomes [8].

Assistive technology and deafblindness

Deafblindness is a unique and isolating sensory disability, resulting from the combination of both hearing and vision loss or impairment that significantly affects communication, socialization, mobility and daily living [9]. Deafblind individuals use AT for the vision impaired, for example, long canes for mobility, screen, reading software, and refreshable braille displays [10,11] and AT for the hearing impaired, for example, hearing aids and cochlear implants, as well as human supports, such as sign language interpreters and communication guides (support workers trained specifically to work one-to-one with people with deafblindness) [12,13]. Much of the research on deafblindness and AT focuses on AT for communication and social inclusion ([10,14–17]) which underpin the functioning of people with deafblindness across all life domains and in all contexts. Vibro-tactile or haptic technology and 3D printing are showing early promise for people with deafblindness, however, these technologies are as yet rarely studied [16].

AT, deafblindness and the Southern African Development Community

The Southern African Development Community (SADC) was selected as the focus of this study. Any research into AT and its impacts must be sensitive to context, and the impact of context upon capability [18]. Reasons for selecting the SADC region included the emergence of an active Pan-African AT Community [19]; evidence of strategic thinking about AT systems within the region [20–22]; and the first Deafblind International Conference planned for Africa in 2022 [23].

People with deafblindness have been identified as being at risk of exclusion from the achievement of human rights or implementation of Sustainable Development Goals (SDGs), with approximately 0.2% of the world's population living with severe deafblindness, and 2% living with “milder forms” of deafblindness [9]. Statistics regarding the prevalence of deafblindness on the African continent are not available, but evidence suggests that in many low- and middle-income countries, only 5–15% of people who require assistive devices receive them [24,25].

Measuring what matters to people living with disability

AT outcomes research can be defined as “*systematic investigation aimed at identifying the changes that are produced by AT in the lives of users and their environments*” [26]. International calls for the sector-wide collection of AT outcomes data have been made for over two decades yet data is still not routinely collected, and consensus has not been reached on priority dimensions to be measured [27]. That said, extensive scholarly work over several decades has produced a range of psychometrically validated measures, authoritatively reviewed in Federici and Scherer’s AT Assessment Handbook (2017) [28].

Two observations can be made about extant outcome measures which explain the formulation of MyATOF as an alternative “starting point” which provides AT users and stakeholders access to a co- designed, evidence-based and holistic set of outcome dimensions.

Firstly, many AT outcome measurement tools collect partial information, as creating psychometrically valid tools necessitates a focal rather than broad lens [29]. AT outcome measures usually relate to specific products, functional impairments or tasks or specific aspects of consumer experience, for example, predisposition to AT [30]; user satisfaction with AT [31], the psychosocial impact of AT [32]; or assessment for AT with individual products. Some approaches combine these validated measures to obtain a fuller picture across dimensions [33] or offer a comprehensive suite of measures, mediated by professionals [34,35].

Secondly, most tools are not designed to be consumer- directed. Existing approaches to identifying changes regarding AT outcomes are subjective (consumer or AT user-generated) and/or objective (assessed by professionals). Consumer perspectives of AT outcomes have long been discussed and may differ from professional views [36]. Fuhrer et al. classify dimensions of significance as proximal outcomes such as functioning, social participation, vocational productivity, sense of control, and distal outcomes such as environments and assistance costs [26]. Jutai et al. propose the dimensions of device effectiveness, social significance, and subjective well-being [37]. In 2013, Lenker and colleagues conducted a study on consumer perspectives of AT outcomes and at the pilot stage learned, through consumer feedback via their reference group, that *“outcomes is a term practitioners and researchers use, created to justify their work...that the term outcomes is not part of the consumer vernacular”* [38,p.375]. The term outcomes, and the changes about which it may be important to establish an outcome response, hold different meanings for consumers. Observing that outcomes research methodologies should reflect consumer perspectives, Lenker et al. identified the dimensions that mattered, and the need for research reporting the costs of AT provision; the impact of AT on participation; and the AT service delivery process [38].

MyATOF was devised to capture the AT user’s perspective across relevant dimensions and comprises a series of questions, which summarise information about the AT user’s needs, goals, and context. Data are captured in the areas of (a) supports, (b) valued outcomes, (c) costs and cost offsets, (d) human rights, (e) service delivery pathway, and (f) customer experience. Table 1 below outlines the operationalization of the six dimensions comprising the Framework.

Data are summarized into report formats, enabling the AT user to inform practitioners and funders regarding a need for specific AT. Since the data fields are benchmarked against international standards and available evidence, MyATOF and its aggregated data set can be used to inform policy, research, and make comparisons around the world.

MyATOF was developed in Australia through an iterative, consultative process, involving a broad range of people with disability, disability professionals including those with experience in deafblindness, and advocates [52–55]. MyATOF has not yet been used with people with deafblindness or outside of Australia, and the aims of this study were to:

- a. determine the relevance and face validity of MyATOF for use with people with deafblindness in the SADC;

- b. refine the tool, if relevant and valid, to increase its relevance and validity in this context;
- c. deepen the understanding of the context of AT provision and use by people with deafblindness in the SADC.

Table 1. Six dimensions of the MyATOF tool.

MyATOF dimension	Operational framework and supporting references
Tool A – My supports	Assistive products and environmental adaptations subset, drawn from ISO 9999 [39] and NED [40] refined for deafblind cohort by author 3 and MyATOF Steering Group.
Tool B – My outcomes	WHO ICF Activity and participation domains [41]
Tool C – My costs	Aspects of cost (direct costs, indirect costs, social return on investment) based on economic pathway analysis from a sector perspective [42–44]
Tool D – My Rights	Subset of 12 Articles from UN CRPD [45,46]
Tool E – The AT Service Delivery Pathway	Six AT service delivery steps [47–50]
Tool F – Customer experience	Eight aspects of customer experience [48,49,51]

Ethical considerations

Approval to carry out this research was obtained on 28 August 2020 from the Cape Peninsula University of Technology (2020FOBREC785). The Participant Information Sheet confirmed participation in the study was voluntary and anonymous. A small gift voucher was offered to participants who completed all rounds of the Delphi study to thank them for their time and input.

Materials and methods

Study design

Delphi methodology was chosen for this study as the purpose of this approach is to achieve consensus or priorities among an expert panel on a certain topic, where agreement was not previously determined [56]. The Delphi method was also chosen as it integrates elements of both qualitative and quantitative methodologies to address a specific research problem, thus yielding a more holistic view of the research issue [57]. Typically 2 or more rounds of questionnaires are sent to the expert panel until a consensus or clear priorities are reached [56]. In this study, two rounds of electronic surveys using the Qualtrics Platform (www.qualtrics.com) were completed. Participants unable to access the electronic survey had the option of being emailed an MS Word version of the survey. A pilot (n=12) was conducted during Phase 1 of the survey to confirm accessibility. Junger et al's [58] recommendations for conducting and reporting on Delphi studies were addressed as follows:

1. Rationale – the rationale for using the Delphi method is outlined above.
2. Planning and design – for round one, the consensus was sought regarding the relevance and validity of each question using quantitative analysis, and an understanding of specific contextual issues was sought using qualitative analysis as explained below. For round two, both agreement and prioritization were looked for using quantitative analysis and a deeper understanding of contextual issues was pursued using qualitative analysis, again as outlined below.
3. Study conduct – the first questionnaire was piloted to check efficacy as reported above. There was no conflict of interest for any of the three researchers, with two researchers being based outside the SADC region and the third researcher having little involvement with the local deafblind community. While high levels of agreement were achieved in both rounds of the study, disagreement on some items in the second round is reported in the results.
4. Reporting – The purpose of the study and rationale for using the Delphi method is articulated above. The recruitment process for and demographic data of the expert panel are outlined under 'study population'. The development of the MyATOF, which formed the basis of the first Delphi round is explained in the introductory section titled 'Measuring what matters to people living with disability'. A detailed description of the data collection and processing analysis are provided in figures and tables below. Limitations and conclusions of the study are made explicit at the end of the paper.

Setting

Southern African Development Community (SADC), established in 1992, is a regional economic community, consisting of 16 low- and middle-income Member States [59].

Study population

A heterogeneous e-Delphi expert panel, representing the diverse stakeholder group across the field of deafblindness in the SADC was selected. The criteria of eligibility to participate in the study were:

- people with deafblindness over 18 years;
- family members of people with deafblindness;
- educators with a minimum of 3 years experience working in deafblindness;
- researchers with a minimum of 3 years experience working in the field of deafblindness;
- service providers with a minimum of 3 years experience working in the field of deafblindness;
- representatives from advocacy groups who had a minimum of 3 years experience in working with people with deafblindness.

Table 2 provides an overview of the demographics of the panelists.

Sampling method

Purposive and snowball sampling were undertaken to develop a list of potential participants for the Delphi expert panel. Selection occurred over 3 weeks (between mid-September and end-October 2020). An email advertisement was circulated to 96 identified stakeholders. Twenty-nine people from 10 countries within the SADC region, of the 96 stakeholders originally identified, agreed to participate and were emailed Participant Information Sheets, a link to the online survey, and the option to obtain an accessible MS Word version of the survey. Three reminders were issued to these 29 potential participants, with only 17 participants (representing 4 countries) responding and completing Delphi Phase 1. Of the 17 participants who completed Phase 1, 15 completed Phase 2 (representing 4 countries). The invitation to complete Phase 2 was provided to the Delphi panel with a 3-week completion period, including two email reminders. The full Delphi questionnaire is available upon request.

Data collection

Participants were asked to look at all MyATOF dimensions and state whether they perceived them to be (a) relevant to people with deafblindness, and (b) relevant to the SADC context. Participants were invited to provide additional comments about each section of the framework. Participants were anonymous to each other and the researchers giving equal opportunity and weighting to the ideas of each panel member [56]. Qualtrics online survey software provided a secure and accessible platform to capture consent and survey responses. Three participants requested MS Word copies of the survey and returned these to the first author who uploaded the responses manually to Qualtrics.

Table 2. Panellist demographics.

Panellist	Country	Gender	Identity	Age (yy.mm)	Experience with DB**	Years of experience
3/0*	Malawi	F	Advocate	35.11	A-DB < 65 A-DB >65	5–10
12/10	Malawi	M	Service Provider Educator, Researcher	33.0	A-DB < 65 C-DB	3–5
18/9	Malawi	M	Advocate	37.3	A-DB < 65 C-DB	3–5
20/6	Malawi	M	Person with Deafblindness Family Member, Educator Researcher, Advocate	39.8	C-DB	3–5
4/15	South Africa	F	Researcher Service Provider	40.1	A-DB < 65 A-DB > 65 C-DB	10–20
5/0*	South Africa	F	Service Provider	47.0	A-DB < 65 A-DB > 65 C-DB	5–10
7/16	South Africa	M	Person with Deafblindness Advocate	62.8	A-DB < 65	10–20
8/12	South Africa	M	Person with Deafblindness Service Provider Educator Advocate	62.11	C-DB	10–20
9/4	South Africa	M	Service Provider Educator	34.1	A-DB > 65	3–5
14/5	South Africa	F	Service Provider	–	A-DB < 65 A-DB > 65 C-DB	20+
17/13	South Africa	F	Person with Deafblindness	50.4	C-DB	20+
15/17	South Africa	F	Person with Deafblindness	43.0	A-DB < 65	20+
16/11	Zambia	F	Family Member, Service Provider Educator, Researcher Advocate	37.4	C-DB	5–10
10/8	Zambia	M	Person with Deafblindness Advocate	–	A-DB < 65	20+

Panellist	Country	Gender	Identity	Age (yy.mm)	Experience with DB**	Years of experience
21/3	Zambia	M	Advocate	-	A-DB < 65	5-10
6/14	Zimbabwe	M	Advocate	58.0	C-DB	20+
13/7	Zimbabwe	M	Educator Researcher, Advocate	40.2	A-DB < 65	10-20
Malawi (4)=23.5%		F=41.2%	Person with Deafblindness=6	Age range	A-DB<65=44%	3-5=23.5%
South Africa (8)=47.0%		M=58.8%	Family Member=2	33-62.8 years	A-DB>65=16%	5-10=23.5%
Zambia (3)=17.7%			Service Provider=7		C-DB=40%	10-20=23.5%
Zimbabwe (2)=11.8%			Educator=6 Researcher=6 Advocate=10	Average age=44.3 years		20+=29.5%

* Panellists who only participated in Phase 1 of the study.

** A-DB < 65=Acquired DB (under 65years of age), A-DB > 65=Acquired DB (over 65years of age), C-DB=Congenital DB (from birth).

Data analysis

Both quantitative and qualitative analyses were undertaken with the data from each Delphi round. Phase 1 responses were downloaded into a CSV file, with duplicates (n¼3) removed. The third author tabulated the quantitative data. The second author conducted an initial, thematic analysis of the qualitative responses using the first four steps outlined by Braun and Clarke [60], transcription (not required for this study), reading and data familiarisation, coding, and searching for themes. Given the specific nature of the comments made by participants, an inductive approach was taken to determine broader themes reflected by the data. The themes arising from the initial analysis of comments made by participants in response to the questions in Phase 1 were reviewed by all authors (stage 4 of Braun and Clarke's process for thematic analysis [60]). The third author identified consistency between the themes emerging from the data and the WHO 5Ps. for example mapping the themes of the cost and lack of availability of AT, as barriers captured by Products, and Policy. Completion of the final two steps of the thematic analysis outlined by Braun and Clarke comprised defining and naming themes (completed by the third author) and finalizing the analysis (undertaken by all three authors, ensuring all the data was consistent with the 5Ps and determining sub-themes for each) [60]. Phase 2 involved asking participants to rate (in order to prioritize) the importance of these themes derived from Phase 1. Participants were invited to provide additional comments (beyond responding to the individual questions). Phase 2 results were downloaded to a CSV file. The second author undertook an analysis of the qualitative data, using the existing themes from Phase 1 and

expanding existing sub-themes or adding new sub-themes if the existing themes did not adequately capture new ideas emerging from the Phase 2 data.

These expanded as well as the new themes were reviewed by authors one and three. Some further modifications were made until consensus was reached by all three authors.

Results

The quantitative and qualitative data from each of the two Delphi phases are presented overleaf. Considerable consistency was observed in both phases, apart from two sub-themes in the second phase. From the qualitative data, key issues were identified to be addressed regarding AT provision to people with deafblindness in the SADC region.

Phase 1 results

Overwhelmingly, 100% of the 17 participants in the Delphi panel, agreed that the set of questions in each section of MyATOF were relevant both to people with deafblindness and the SADC context. See Figure 1 for results of the quantitative data collection during Phase 1.

A summary of the qualitative data for each tool is presented below, followed by the 20 sub-themes organized against 5key themes, which were consistent with the WHO 5Ps [8].

Tool A – My supports: What AT and other things do I use?

Prompts included examples of AT supports [39] as follows: hearing amplification (e.g., hearing aids); low technology magnifiers (e.g., magnifying glass); high technology magnifiers (e.g., closed- circuit television); mobility products (e.g., long cane); visual or tactile alert devices and systems; screen enlargement software; screen reading software; refreshable braille displays; visual or tactile labels; human supports (e.g., interpreter, intervenor, communication guide, technology trainer, support worker, personal assistant); and environmental supports (e.g., large signs, braille signage, tactile ground surface indicators, audible traffic lights, and other audible signals).

In their responses, the panellists described the use of AT as enabling the achievement of outcomes and endorsed and expanded the sub-set of products suggested for deafblindness, noting that *“Assistive technologies have played a pivotal role in helping the deafblind”* (Panellist 21/3). Barriers include lack of access, appropriateness, training, availability, knowledge and family commitment and high cost, for example, *“the inclusion of assistive technologies for the deafblind come[s] with financial obligations and still there has no[t] been commitments towards making the environment adaptable for the inst[all]ation of assistive technologies”* (Panellist 21/3). These themes relate to the “Products” and “People” principles of the WHO 5Ps.

Tool B – My outcomes: What does my AT enable me to do?

Prompts included the WHO activity and participation domains, suggesting that AT enables participation in mobility; self-care; communication; managing general tasks

and demands (such as handling money, paying bills, organizing the day); managing domestic life (such as cooking, washing clothes, cleaning the home); learning and applying knowledge (e.g., remembering, writing, reading); relationships with others; an educational life (learning); an economic life (working, volunteering); a civic life (being part of the community); recreation and leisure; a spiritual life (able to worship); and political life (able to vote in person) [7,24].

Panellists endorsed the broad spectrum presented, with statements such as “everything is captured here” (Panellist 16/11) and identified an array of outcomes that are possible but yet not achieved in their country owing to a perceived lack of awareness of deafblindness in society, the need for knowledge/training in AT to assist interpreting guides to improve access, and the need for vocational guidance. One panellist (6/14) noted that *“In most cases, deafblind do not have access to AT, making their lives difficult and unbearable”*.

Tool Statement Relevance

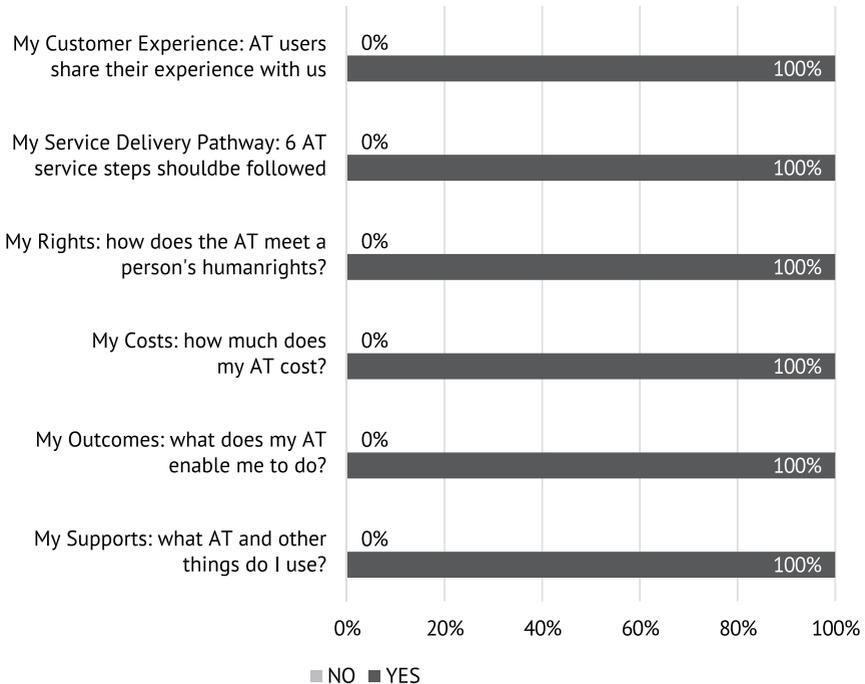


Figure 1. Relevance of MyATOF statements to people with deafblindness and the SADC region.

Tool C – My costs: How much does my AT cost? How much does my AT save?

Prompts provided definitions of costs (the price of the AT and any costs involved in set-up and maintenance); cost savings (including money that could be saved by the

user or the government, by using AT. For example, a user might not need to purchase another piece of equipment or might need less support work hours); and downstream cost savings (avoiding costs in the future by investing in AT now. For example, if AT supports a user's health, independence and safety, this might save visits to the doctor or to hospital).

Panellists identified costs as a major barrier because of "prohibitive AT costs" (Panellist 6/14) and noted that *"AT is only available to those who can afford it. Government is not set-up for ... ATs"* (Panellist 5/0). A range of actions was proposed, including subsidies, import duties, and in-country production, which might address these issues in part. Solutions required action in the Policy and Products areas of the WHO GATE's agenda.

Tool D – My Rights: How does AT meet a person's human rights?

Prompts included a list of rights from the United Nations Convention on the Rights of Persons with Disabilities [45] (Article 4: General obligations; Article 5: Equality and non-discrimination; Article 9: Accessibility; Article 19: Living independently and being included in the community; Article 20: Personal mobility; Article 21: Freedom of expression and opinion, and access to information; Article 24: Education; Article 25: Health; Article 26: Habilitation and rehabilitation; Article 27: Work and employment; Article 29: Participation in political and public life; Article 30: Participation in cultural life, recreation, leisure and sport; other articles of relevance).

Panellists described a lack of realization of rights, for example, *"normally, deafblind persons rights are not made possible, for example, the right to education, independent mobility, participation in society, etc."* (Panellist 6/14). Lack of knowledge regarding basic human rights was linked to advocacy: *"It is vital for the deafblind persons to be familiar with UNCRPD because it is an advocating tool for full inclusion and availability of accessible services"* (Panellist 11/0). Roles for government and civil society (such as private companies) were identified: *"Government is also not ready to implement most of these rights"* (Panellist 5/0). The themes in the data about lack of implementation and lack of knowledge of rights, related to the "Policy" and "People" principles of the WHO 5Ps.

Tool E – The AT Service Delivery Pathway

The pathway has been conceptualized as initiation, assessment, trial and solution selection, procurement, implementation (delivery/setup/trial), follow-up, and review [50,61].

Panellists endorsed the notion of a service delivery process, noting that *"if one step is skipped the clients [might] be given wrong AT"* (Panellist 20/06). Panellists suggested that services could be provided at various levels of skill and noted that there was no service delivery model of this kind in Africa, with one panellist stating that these steps were *"currently not possible in Africa"* (Panellist 6/14). These findings related to the "Provision" principle of the WHO 5Ps.

Tool F – Customer experience

Based on the following prompts, drawn from the experience of Australian AT users [51], panellists said they wanted:

- the best combination of devices, personal care, and environmental design;
- access to sufficient funding for good quality and long-lasting devices;
- funding to meet AT needs in every area of life, based on a holistic assessment of needs, so that each product works well and does not interfere with other supports;
- consideration of AT needs across people's lifespan and as needs change;
- support throughout the process of obtaining AT, including product trial, training, and maintenance;
- access to resources when needed;
- active involvement in decision-making;
- consideration of personal preferences and identity so that AT is chosen to suit lifestyle and participation.

Rather than responses about being a consumer, this section elicited comments regarding inclusion, rights, and expertise, which are precursors to having a positive customer experience. Panellists identified the scarcity of AT and specific design features that would contribute to participation and inclusion; a lack of services: *"In Africa there is hardly any existence of specialised services for deafblind persons"* (Panellist 19/0); and the human right that: *"Deafblindness must be treated equal like everyone"* (Panellist 9/4). Aspirations included the hope that *"deafblind persons in [the] African continent should also take part in ensuring full inclusion, participation, budgeting, and implementation of AT-related services"* (Panellist 11/0). The themes related to the "Personnel" principle of the WHO 5Ps.

See Table 3 in the section below for the Phase 2 data for the five key themes and sub-themes identified in Phase 1.

Phase 2 results

In the Phase 2 survey, panel members were invited to identify the level of importance that each of the 20 sub-themes, derived from the Phase 1 data, held for addressing the assistive technology needs of people with deafblindness in the SADC region.

Table 3 shows the responses of the panellists to the themes, derived from the Phase 1 data, regarding their importance in furthering AT outcomes for people with deafblindness in the SADC region. Of the six themes, which all participants counted as very important, *"Governments need to play more of a role in AT provision"* was reiterated frequently in the comments of the Delphi panel, for example, *"I would suggest that government[s] in Africa need to play a big role and en[s]ure that more AT are provided in Africa"* (Panellist 16/11).

Six of the 20 sub-themes were viewed as being very important by all members of the Delphi panel:

- Raise awareness of deafblind people about social inclusion.
- Government must implement the CRPD (human rights conventions).
- Governments should make AT that is relevant to people with deafblindness available.
- Governments need to play more of a role in AT provision.
- There is a need for staff awareness about deafblindness and skills development in general health and disability services.
- There is a need for staff awareness about deafblindness and skills development in all areas of government and social services.

Most of the sub-themes were viewed as being very important by more than two-thirds of the Delphi panel, with the remaining members viewing them as quite important.

Only the following two sub-themes were viewed as being not important by some members of the Delphi panel:

- Deafblind persons should contribute to the cost of their AT (5 participants indicated “not important”).
- AT products are not available because they are not produced in African countries (1 participant indicated “not important”).

Table 3. Summary of Phase 2 data sub-themes.

Theme 1 – PEOPLE and sub-themes	
a.	Raise awareness of deafblind people about social inclusion
b.	Raise awareness of deafblind people about their human rights
c.	With the right assistive products and services, people with deafblindness can become employed
d.	There is a need to develop the assistive-technology-related skills of family members and family and support networks
e.	Value of peer support
Theme 2 – POLICY and sub-themes	
a.	Government must implement the UNCRPD (human rights convention)

Theme 2 – POLICY and sub-themes

- b. Policy should support deafblind persons by paying for AT
- c. Deafblind persons should contribute to the cost of their AT
- d. Governments should make AT that is relevant to people with deafblindness available
- e. That policies are actioned
- f. People with deafblindness should be involved in the process of developing AT policies

Theme 3 – PRODUCTS and sub-themes

- a. AT products are not available because they are not affordable for most people with deafblindness
- b. AT products are not available because they are not produced in African countries
- c. AT products are not available because they are imported and there are big costs with import duty and foreign exchange
- d. Physical environments are not adaptable or accessible. The interface between AT and environments must be considered
- e. Products must be user-friendly/easy to use (not complicated) and durable

Theme 4 – PROVISION and sub-themes

- a. There is limited availability of AT products or services to people with deafblindness in my experience.
- b. Governments need to play more of a role in AT provision (noting roles undertaken by civil society including large corporates, donors and advocacy groups)
- c. It is helpful to know where to go for advice and for products
- d. Empower deafblind people with AT as it is cost effective compared with human supports
- e. Strategies and processes to ensure provision in rural areas

Theme 5 – PERSONNEL and sub-themes

- a. There is a need for staff awareness about deafblindness and skills development in general health and disability services

Theme 5 – PERSONNEL and sub-themes

- b. There is a need for staff awareness about deafblindness and skills development in all areas of government and social services
- c. It is important to provide training (AT services) as well as AT products
- d. It would be useful to have a training package about deafblindness and AT, as well as training packages available at tertiary student and workforce levels
- e. Need for cultural/religious awareness and sensitivity to age

PEOPLE: Sub-themes

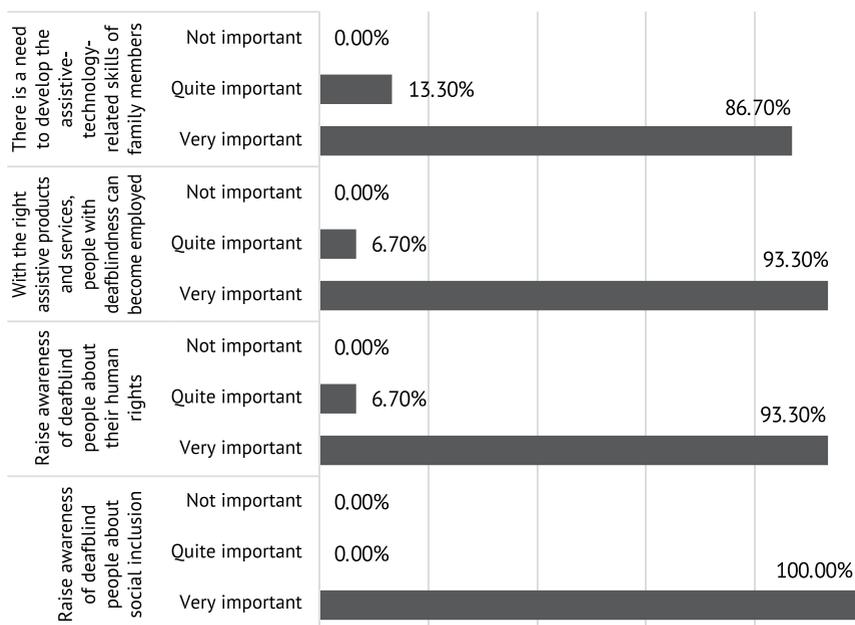


Figure 2. Rating of the importance of sub-themes of the “People” theme.

Additional comments were added by panellists to the Phase 2 questionnaire. Most comments reiterated existing sub-themes, but some new themes emerged, and some existing themes were extended. New and extended sub-themes, that emerged from comments submitted during the Delphi Phase 2, have been described below.

Theme 1: people

In their responses (refer to Figure 2), panellists identified the key role of stakeholders, their awareness, knowledge, and exposure, in realizing the potential of using

assistive products to achieve the quality of life, productivity, access to opportunities, and enabling people to *“follow our dreams to fulfil our passion and enrich others lives”* (Panellist 15/17). Systemic barriers, such as lack of access to information, inadequate or ineffective policy and legislation, and lack of availability in early childhood settings and schools were identified.

Based on the data from Phase 2, the fourth sub-theme was extended to *“There is a need to develop the assistive-technology- related skills of family members and support networks”* and an additional theme was identified: *“The value of peer support”*.

POLICY: Sub-themes

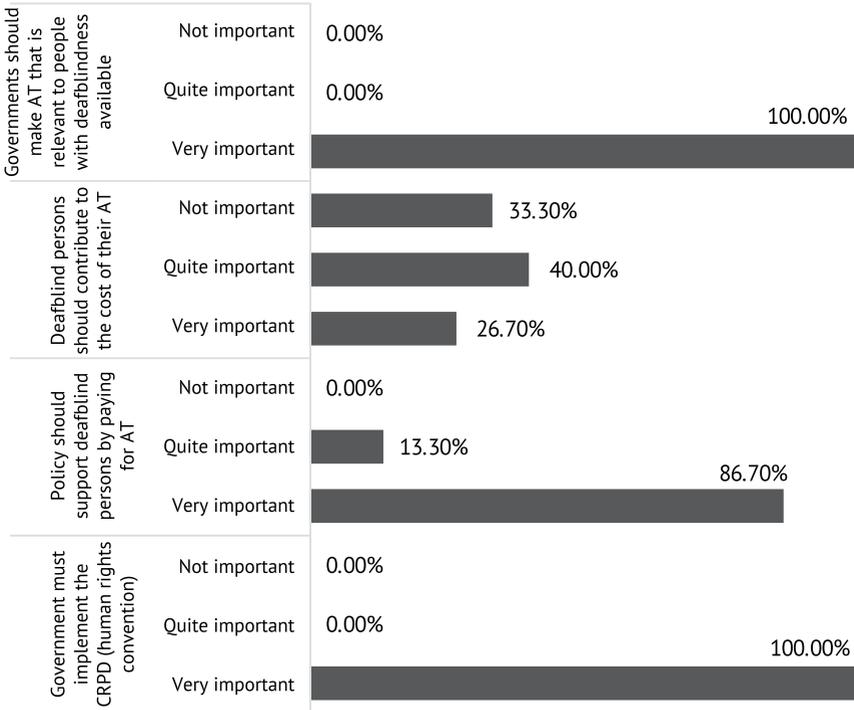


Figure 3. Rating of the importance of sub-themes of the “Policy” theme.

Theme 2: policy

Policy was regarded as being a highly relevant aspect of access to AT, with panellists identifying the impact of policies upon costs and financial access (refer to Figure 3). Some policy solutions were offered to legislate the right to AT and to enforce compliance, for example, *“AT should be legalised and a mandatory requirement for all public and private institutions”* as well as social protection (Panellist 21/3); affordability: *“Not all can manage to contribute something towards AT as most of them come from very poor families”* (20/06); and nuanced inclusion of people with deafblindness in

general policy. Civil society, as well as government, were regarded as duty holders to enact better policies, and organizations for people with disabilities should prioritize the matter in their advocacy work (6/14). There was strong concurrence by panellists on all themes except the question of who should pay for AT.

Two new themes were identified: *“The need for policies about AT to have an implementation plan and to be actioned”*, and that: *“People with deafblindness themselves should be involved in the process of developing AT policies”*.

PRODUCTS: Sub-themes

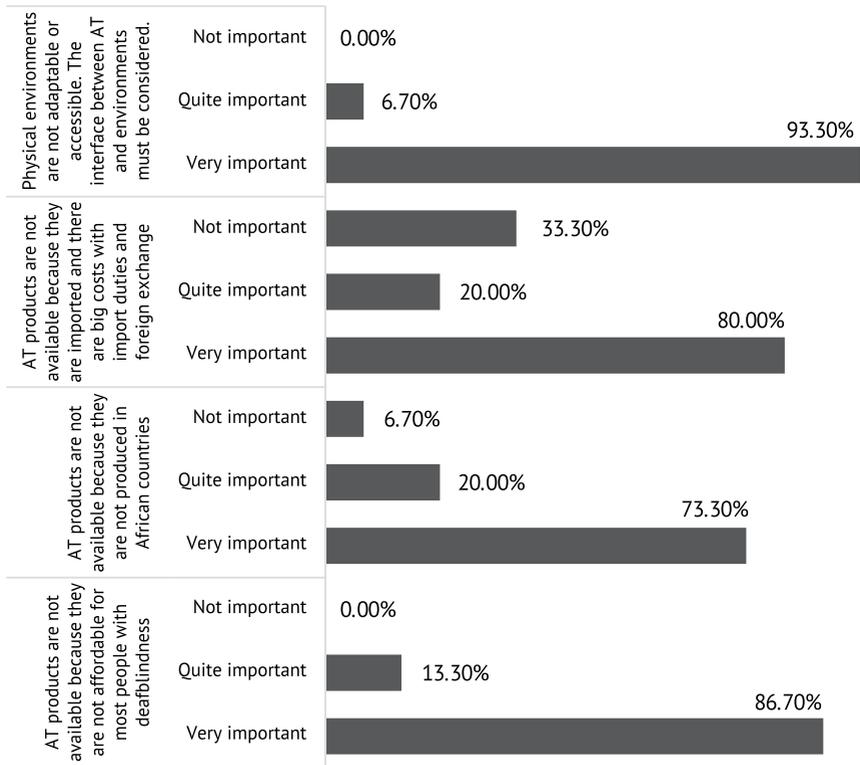


Figure 4. Rating of the importance of sub-themes of the “Products” theme.

Theme 3: products

Broad agreement was evident across themes, with panellists noting that AT products play a critical role: *“Braille and Assistive Listening Technology are the most important methods (refer to Figure 4). Deafblind people can experience the world of sound”* (Panellist 15/17). *“AT products should indeed be affordable and reliably supplied”* (Panellist 12/10). Panellists were divided over whether AT is best produced locally or whether import barriers should be lifted, with suggestions including both lowering of taxes

and increasing design and production in Africa: “Governments must waive all import excise and customs duties on AT products...Governments must facilitate local design and manufacture of AT products which adequately meet the needs of their respective deafblind communities” (Panellist 7/16).

A fifth theme was identified also that: “AT needs to be user- friendly/easy to use, and durable”.

PROVISION: Sub-themes

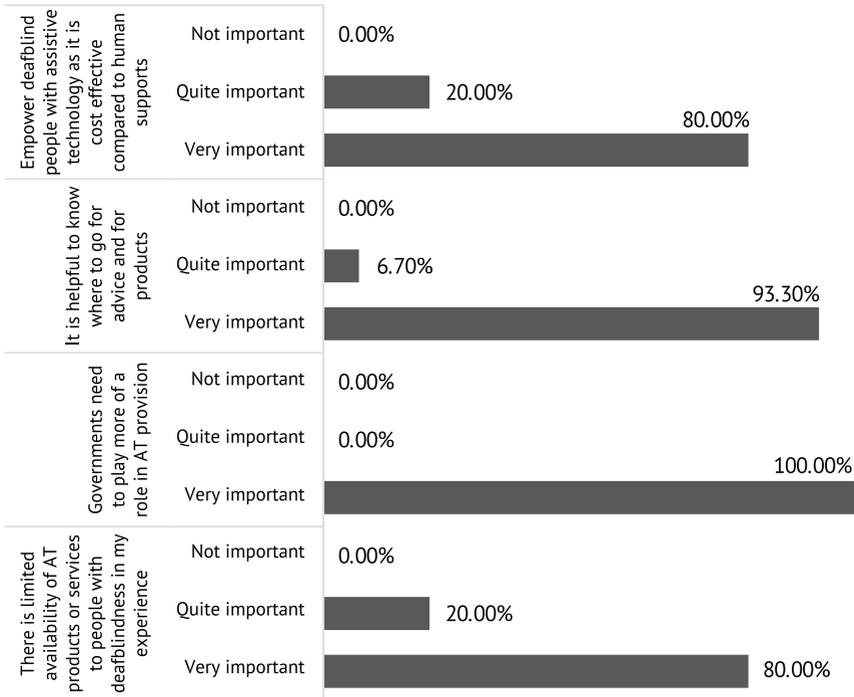


Figure 5. Rating of the importance of sub-themes of the “Provision” theme.

Theme 4: provision

The comments submitted by panellists were consistent with original themes and with the WHO. Data from Phase 1 and Phase 2 (refer to Figure 5) indicated the relevance of the AT service delivery steps, which constitute “good practice” in AT provision, that is, awareness: “More awareness raising on assistive technology available and on what deafblind community unique needs are” (Panellist 8/12); advice, education, maintenance: “Having places where [to] get advice on how to use and care [for] AT” (Panellist 20/6); and provision, all underpinned by the fundamentals of rights: “Primary health and government must come on board with the provision of assistive technology” (Panellist 8/12); and enabling attitudes: “There is need to combat negative beliefs about AT provisions, such as AT provisions are a budget constraint” (Panellist 21/3).

The second sub-theme was extended to: “Governments need to play more of a role in AT provision (noting roles undertaken by civil society including large corporates, donors, advocacy groups)”, and a new sub-theme was added: “There is a need for strategies and processes to ensure AT provision in rural areas”.

PERSONNEL: Sub-themes

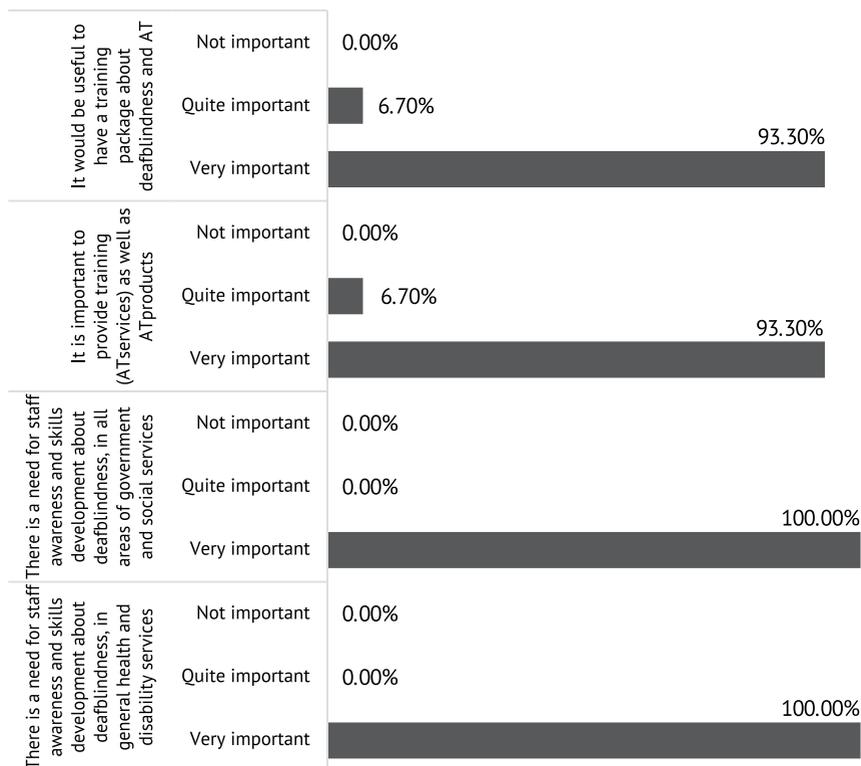


Figure 6. Rating of the importance of sub-themes of the “Personnel” theme.

Theme 5: personnel

A very high level of concurrence with the themes was noted. The panellists provided a clear picture of the pivotal role of personnel in enabling AT access and use (refer to Figure 6). A need for targeted education at vocational and higher education levels was identified repeatedly: “AT training must be offered to institutions and NGOs that provide services to deafblind learners, adults and their families/caregivers” (Panellist 7/16).

A blueprint for addressing this was offered: “DeafBlind South Africa [has] a dream of establishing a development centre for the deafblind community, family and caregivers to provide the distribution and skilled training on assistive technology as well as living

skills training, central social services, occupational therapy service and counselling services. It is a whole one-stop package we would like to provide to the DeafBlind community – but infrastructure costs is our greatest stumbling block due to a lack of funding!” (Panellist 8/12).

From the data provided in Phase 2, the fourth sub-theme was extended to: *“It would be useful to have a training package about deafblindness and AT and training packages available at tertiary student and workforce levels”*, and a fifth theme emerged as: *“[A] need for cultural/religious awareness and sensitivity to age of client”*.

Discussion

The discussion of the findings of this study has been presented according to the three aims of the study.

How relevant and valid is MyATOF for use with people with deafblindness in the SADC region?

This study found the MyATOF dimensions to be relevant and hold face validity, suitable for use with people with deafblindness in the four countries represented, namely, Malawi, South Africa, Zambia and Zimbabwe. The dimensions (supports, outcomes, costs, rights, and service delivery) were recognizable to the panellists, and strongly related to the issues that the panellists faced. A powerful theme of AT under-realization or unavailability pervaded the Delphi responses. This was consistent with the Australian experience, where AT users noted that they might not have the supports required to realize potential outcomes fully or to meet their human rights fully [53,54]. Similarly, service-delivery contexts might not provide a satisfactory service-delivery outcome or customer experience. However, the data collected from Africa suggested a far higher level of under-realization, particularly in the latter dimension of customer experience.

While all fourteen countries in the SADC region were targeted during the recruitment phase of this study, panellists represented only four countries, so it is not possible to extrapolate to the whole SADC region.

What refinements to MyATOF might be required to increase its relevance and validity in this context?

The data from the Delphi study revealed underlying issues in AT systems within four countries within Southern Africa, which influence the capacity of people with deafblindness to realize their potential to participate fully in AT as measured by MyATOF. Analysis using the systems lens of WHO 5 P's has illuminated the forcefield of supply network and social policy issues which underpin the realization of rights and outcomes for people using AT. Based upon these findings, MyATOF does not require refinement in its dimensions or granularity. Nevertheless, foregrounding a person's context will be considered in the next iteration of the framework, that is, specifying and naming the impact of systems upon an individual.

An analysis of the panellists' countries of origin demonstrated differences between economic status [18] which could have influenced the responses received. Malawi is considered to be a low- income country, remaining one of the poorest countries in the world; Zambia, with its stalled economy, along with Zimbabwe, currently in an economic crisis, are both classified as lower-middle-income countries; and South Africa is considered to be an upper-middle-income country, despite having one of the highest inequality rates in the world.

Common responses, received from panellists outside South Africa, referred to the need for cogent AT policy, access to AT (free or at low cost or through donations), local manufacturing to reduce costs and increase access, the need for social protection, organizations of persons with disability (OPDs) to advocate for AT, and that AT that is provided/made available is context relevant. Panellists from South Africa, on the other hand, highlighted the need for legislation, focusing on the human rights element and the provision of AT through resource centres and new supply chains. There was also an expressed need concerning training in AT across all levels of education, that is, primary, secondary and post-secondary. These differences could be ascribed to varying country contexts, including economic, social and political disparities. Further specific research is required to better understand commonalities and differences between countries in Africa.

What has been learned about the context of AT provision and use by people with deaf-blindness in the SADC region?

Findings and implementation priorities from the data have been presented according to the WHO 5 P's [7]:

People

The WHO proposes the following principles related to AT People (users and families). Involving users and their families in all interventions is crucial. A user-centred approach is critical to make sure that users' needs are addressed when developing policies and provision of services. Services should not just be accessible physically, but also appropriate culturally and tailored to users' needs [7].

The panellists concurred, noting that the circle of support for people with deaf-blindness includes teachers and communication partners, and calling for a societal attitudinal change towards a focus on abilities, not disabilities.

Policy

In terms of AT Policy, the WHO proposes that countries should develop national policy and programmes to ensure everyone, everywhere can access assistive products. The WHO is building assistive technology assessment toolkits and guidance on financing mechanisms to ensure the sustainability of service provision and universal access, as well as producing guidance also on the implementation of a Priority Assistive Products List with minimum standards, appropriate training, and service provision [7].

The top priorities of the panellists included: laws to ensure access to AT to support learning and independence; governments to implement their commitments to pol-

icy and be held accountable; and governments to fund AT to increase access and to provide social protection. Panellists called specifically for people with deafblindness to be consulted and involved with the development of AT-related policies, and that access to AT should be assured through governments as well as the private sector, while organizations of people with disabilities should prioritize advocacy for improved AT policies.

Products

The WHO promotes a range of strategies to strengthen product availability including the WHO Priority Assistive Products List [62]. This encourages countries to develop a list of national priority products and is a guide to enhance production, procurement and service provision, to develop reimbursement policies and to shape markets [7].

The panellists agreed with the sub-set of AT for deafblindness presented in this research, noting several additional products (e.g., Job Access Without Speech (JAWS) screen reading software) and focussing on supply network issues. Congruent with the WHO view of market-shaping referred to above, top priorities included removal of import barriers and taxes, and enhanced local manufacturing to reduce costs and ensure availability; also, high- quality and fit-for-purpose products, utilization of alternate funding pathways and innovative supply options such as refurbishment and redistribution of AT products.

Provision

The WHO suggests that AT service provision should include universal access and should enable early intervention. People should be able to access assistive products for all their functional needs from a single point. The WHO is developing guidance on innovative models of service provision around the globe. Fundamental components include (a) health systems that make service provision for assistive products, and (b) networks of specialist referral centres connected to primary healthcare infrastructure [7].

The panellists supported the call for universal access and early intervention. The specific specialist set of skills for working with deafblindness reinforced the notion of single points of service, possibly with prioritized access to information, for example, resource centres. Other priorities included knowing what is available, trialling products, and guidance on care and maintenance. A business case for investment in AT by governments was proposed, with a focus on services and support in rural, not only urban, areas and, with the aim of realizing human rights, safety, security, independence, and access to information.

Personnel

AT Personnel, as defined by WHO, must be available and accessible to AT users and possess skills in culturally safe assessment and prescription, fitting and user training, follow-up, maintenance and repairs. A WHO Assistive Products Training Package is underway to develop skills in providing AT to support countries in building the capacity of their community-level workforce [7].

The panellists concurred on the need for widespread training for people with deafblindness and their families and extends to civil society and professionals. A point

that differed from the WHO stance, specific to deafblindness, was the need for specific training of personnel in deafblindness, in particular, deafblind communication methods. Further, panellists called for AT service provision to be included in relevant curricula, for example, in all health sciences fields with a focus on vocational education and the need for continuous professional development (CPD). Further priorities outlined were training of service providers and other individuals working with people with deafblindness and for information related to AT products to be accessible (in multiple languages) and comprehensible.

Strengths and limitations

MyATOF is a data capture and storytelling tool under development, without the psychometric properties of formal AT outcome measures. It does not replace formal outcome measurement but, as a consumer-focussed, whole-of-system approach, it fills a gap in capturing and systematizing experiential knowledge.

All key stakeholder groups were represented on the Delphi panel, however, only 4 of the 14 countries in the SADC region were represented in the data from the second survey. While the data were consistent, it is necessary to seek data from other SADC countries in future studies in order to better understand the situation within the whole region.

Implications and recommendations

Researchers must consider the context in which they are situated to capture the impact of socio-political and economic systems on the AT user [63,64]. This study indicated that supports, outcomes, costs, rights, service delivery steps and customer experiences (dimensions captured with MyATOF framework) are relevant to people with deafblindness in 4 countries in the SADC region. It identified that stakeholders see MyATOF dimensions as relevant to express the realities of life for AT users and to raise awareness of the potential outcomes of AT and its current undersupply. In Australia, AT users utilize the self-reports generated by the MyATOF online tool to support discussions between AT users and AT funders within existing AT service delivery frameworks or use their data to lobby for the improvement of systemic AT issues such as inequitable funding. Furthermore, this study suggests that considerable work is required to improve systemic access to AT in the Southern African context. Local stakeholders may, like their Australian counterparts, choose to tell their stories of “rights met and unmet” using these 6 dimensions and to engage in systemic advocacy and empowerment initiatives to alert relevant duty bearers to improve services, systems and therefore outcomes.

Conclusion

While contexts differ, AT users globally, including those with deafblindness, share common, unifying, human experiences and aspirations. In MyATOF these are conceptualized as supports, outcomes, costs, rights, service delivery steps and customer experiences, and are operationalized using available taxonomies and evidence.

The results of the Delphi process undertaken with deafblind stakeholders across 4 countries in the SADC region support the face validity of the framework dimensions. Analysis of the data suggested that the experience of accessing AT and achieving participation outcomes is extremely challenging, and the evidence generated could be clearly mapped onto an AT systems view based on the WHO 5Ps model. This is a critical point, as the achievement of individual outcomes must be viewed in the context of systemic barriers. From a human rights perspective, it appears that tools such as those offered by MyATOF have the potential to enable the collection of individualized data and self-advocacy and to contribute to the systemic advocacy necessary for the realization of rights. It is hoped that the MyATOF platform contributes to the state of the art in AT research by guiding consumers and their AT practitioners to report the outcomes of their AT solutions across a range of impact areas.

Acknowledgements

The authors wish to thank Deafblind International for providing financial support through a competitive grant through the African Research Initiative to undertake this project.

Disclosure statement

No potential conflict of interest was reported by the author(s). The views expressed in the submitted article are the authors' own and not an official position of their institutions or the funder.

Funding

This project was funded with a competitive grant from the Deafblind International African Research Initiative.

ORCID

Diane Bell <http://orcid.org/0000-0003-2139-0012> Meredith Prain <http://orcid.org/0000-0001-9459-4214> Natasha Layton <http://orcid.org/0000-0002-3213-8069>

Data availability statement

Data from the two Delphi rounds are available from the first author upon request. Further information on the MyATOF Framework is available from the third author upon request.

References

- [1] Groce N, Kett M, Lang R, et al. Disability and poverty: the need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*. 2011;32(8):1493–1513.
- [2] Hosseinpoor AR, Stewart Williams JA, Gautam J, et al. Socioeconomic inequality in disability among adults: a multicountry study using the world health survey. *Am J Public Health*. 2013;103(7):1278–1286. [3]Khasnabis C, Mirza Z, MacLachlan M. Opening the GATE to inclusion for people with disabilities. *The Lancet*. 2015; 386(10010):2229–2230.
- [4] Borg J, Östergren P, Larsson S, et al. Assistive technology use is associated with reduced capability poverty: a cross-sectional study in Bangladesh. *Disabil Rehabil Assist Technol*. 2012;7(2):112–121.
- [5] Tebbutt E, Brodmann R, Borg J, et al. Assistive products and the sustainable development goals (SDGs). *Global Health*. 2016;12(1):1–6.
- [6] MacLachlan M, McVeigh J, Cooke M, et al. Intersections between systems thinking and market shaping for assistive technology: the SMART (Systems-Market for assistive and related technologies) thinking matrix. *IJERPH*. 2018;15(12):2627.
- [7] World Health Organisation. Policy brief: access to assistive technology. Geneva (Switzerland): WHO; 2020.
- [8] MacLachlan M, Scherer M. Systems thinking for assistive technology: a commentary on the GREAT summit. *Disabil Rehabil Assist Technol*. 2018;13(5):492–496.
- [9] World Federation of the Deafblind. At risk of exclusion from CRPD and SDGs implementation: inequality and persons with deafblindness. Geneva (Switzerland): World Federation of the Deafblind; 2018.
- [10] Cantin S, De Abreu Cybis W, Trudeau S, et al. Assessment of a communication assistive technology for individuals with deafblindness: a case study. *JDBSC*. 2019;5(1):73–95.
- [11] Cantin S, de Abreu Cybis W, Durocher N. Setup by a person with deafblindness of a face-to-face communication assistive technology based on generally available applications. *Disability and Rehabilitation: Assistive Technology*. 2020; 1–7. DOI:10.1080/17483107.2020.1751315
- [12] Wittorff MM. Communication guide support for Western Australians with deafblindness: a pilot project. Perth (Australia): Curtin University; 2014; p. 214.
- [13] Raanes E, Berge SS. Sign language interpreters use of haptic signs in interpreted meetings with deafblind persons. *Journal of Pragmatics*. 2017;107:91–104.

- [14] Hatakeyama T, Watanabe T, Takahashi K, et al. Development of communication assistive technology for persons with Deaf-Blindness and physical limitation. *Stud Health Technol Inform.* 2015;217:974–979.
- [15] Dyzel V, Oosterom-Calo R, Worm M, et al. Assistive technology to promote communication and social interaction for people with deafblindness: a systematic review. *Front Educ.* 2020;164.
- [16] Wittich W, Granberg S, Wahlqvist M, et al. Device abandonment in deafblindness: a scoping review of the intersection of functionality and usability through the international classification of functioning, disability and health lens. *BMJ Open.* 2021;11(1):e044873.
- [17] Perfect E, Jaiswal A, Davies TC. Systematic review: Investigating the effectiveness of assistive technology to enable internet access for individuals with deafblindness. *Assist Technol.* 2019;31(5):276–285.
- [18] The World Bank. Inclusion matters - the foundation for shared prosperity. Washington (DC): World Bank; 2013.
- [19] Layton N, Bell D, Buning ME, et al. Opening the GATE: systems thinking from the global assistive technology alliance. *Disabil Rehabil Assist Technol.* 2020; 2020/07/0315(5): 484–490.
- [20] Matter RA, Eide AH. Access to assistive technology in two Southern African countries. *BMC Health Serv Res.* 2018; 18(1):792. DOI:10.1186/s12913-018-3605-9
- [21] Matter R. What works to increase access to assistive technology in Southern Africa. Cape Town (South Africa): University of Cape Town; 2020.
- [22] Visagie S, Scheffler E, Seymour N, et al. Assistive technology service delivery in South Africa: conceptualising a systems approach. In: Kathard H, Padarath A, Galvaan R, editors. *South African health review.* Durban (South Africa): Health Systems Trust; 2020.
- [23] Deafblind Australia. What is deafblindness Australia [Internet]. Burswood (Australia): Deafblind Australia; 2021 [cited 2021 January 30]. Available from: <https://www.deafblind.org.au/deafblind-information/what-is-deafblindness/>
- [24] World Health Organisation. World report on disability. Geneva (Switzerland): World Health Organisation; 2011.
- [25] Matter R, Harniss M, Oderud T, et al. Assistive technology in resource-limited environments: a scoping review. *Disabil Rehabil Assist Technol.* 2017; 2017/02/1712(2):105–114.
- [26] Fuhrer MJ, Jutai JW, Scherer MJ, et al. A framework for the conceptual modelling of assistive technology device outcomes. *Disabil Rehabil.* 2003;25(22):1243–1251.

- [27] Smith R, Scherer M, Layton N. Committing to AT outcomes and synthesizing practice, research and policy. In: Layton N, Borg J, editors. *Global perspectives on assistive technology: proceedings of the GReAT Consultation 2019*. Geneva (Switzerland): World Health Organization; 2019. p. 196–217.
- [28] Federici S, Scherer M, editors. *Assistive technology assessment handbook*. Boca Raton (FL): CRC Press; 2017.
- [29] Dijkers M. When the best is the enemy of the good: the nature of research evidence used in systematic reviews and guidelines. Austin (TX): NCDDR Task Force on Systematic Review and Guidelines; 2009.
- [30] Federici S, Scherer MJ, Ehrlich-Jones L. Measurement characteristics and clinical utility of the assistive technology device predisposition assessment (ATD PA) among mixed patient populations. *Archives of Physical Medicine and Rehabilitation*. 2021;102(4):805–806.
- [31] Demers L, Weiss-Lambrou R, Ska B. The Quebec user evaluation of satisfaction with assistive technology (QUEST 2.0) An overview and recent progress. *TAD*. 2002;14(3):101–105.
- [32] Day H, Jutai J. Measuring the psychosocial impact of assistive devices: the PI-ADS. *Canadian Journal of Rehabilitation*. 1996; 9(2):159–168.
- [33] Andrich R. Tracking individual assistive technology interventions and measuring their outcomes. In: Miesenberger K, Fels D, Archambault D, Peñáz P, Zagler W, editors. *Computers helping people with special needs*. Cham (Switzerland): Springer; 2018.
- [34] Wessels R, Persson J, Lorentsen O, et al. IPPA: individually prioritised problem assessment. *TAD*. 2002;14(3):141–145.
- [35] Scherer MJ. *Living in the state of stuck: how assistive technology impacts on the lives of people with disabilities*. 4th ed. Brookline (MA): Brookline Books; 2005.
- [36] Wessels RD, de Witte L, van den Heuvel W. Measuring effectiveness of and satisfaction with assistive devices from a user perspective: an exploration of the literature. *TAD*. 2004;16(2):83–90.
- [37] Jutai J, Fuhrer MJ, Demers L, et al. Toward a taxonomy of assistive technology device outcomes. *American Journal of Physical Medicine and Rehabilitation*. 2005;84(4):294–302.
- [38] Lenker J, Harris F, Taugher M, et al. Consumer perspectives on assistive technology outcomes. *Disabil Rehabil Assist Technol*. 2013;8(5):373–380.
- [39] ISO. *ISO 9999 Assistive products for persons with disability – Classification and terminology*. 2016.

- [40] NED. Australia's National Equipment Database. 2021. [cited 2021 Sep 18]. Available from: <https://www.askned.com.au/>
- [41] World Health Organization. International classification of functioning, disability and health: ICF. Geneva (Switzerland): World Health Organization; 2020.
- [42] Layton N, Shih S. Economic pathway analysis for assistive technology: a pilot study from Australia. Paper presented at the RESNA Annual Conference; 2018 August 3; Arlington, VA.
- [43] Layton N, Irlam C. Assistive technology for older Australians: rapid evidence review and economic pathway analysis. Canberra (Australia): National Aged Care Alliance; 2018.
- [44] Carter R, Vos T, Moodie M, et al. Priority setting in health: origins, description and application of the Australian Assessing Cost-Effectiveness initiative. *Expert Rev Pharmacoecon Outcomes Res.* 2008;8(6):593–617.
- [45] United Nations. Convention on the rights of persons with disabilities and optional protocol. Geneva (Switzerland): United Nations; 2006.
- [46] Watchorn V, Layton N. Advocacy via human rights legislation - the application to assistive technology and accessible environments. *Australian Journal of Human Rights.* 2011; 17(1):117–138.
- [47] Desideri L, Salatino C, Pignini L, et al. Using a standard procedure to assess assistive technology service delivery outcomes: a proposal from the Italian network of independent assistive technology centres. In: Layton N, Borg J, editors. *Global perspectives on assistive technology: proceedings of the GREAT Consultation 2019.* Geneva (Switzerland): WHO; 2019.
- [48] Dijkstra BPJ, Wessels RD, de Vlieger SLM, et al. KWAZO, a new instrument to assess the quality of service delivery in assistive technology provision. *Disability and Rehabilitation.* 2006; 2006/01/0128(15):909–914.
- [49] Larsson Ranada Å, Lidström H. Satisfaction with assistive technology device in relation to the service delivery process-A systematic review. *Assist Technol.* 2019;31(2):82–97.
- [50] AAATE. Excellence in the process of AT provision. Linz (Austria): Johannes Kepler University; 2018.
- [51] De Jonge D, Layton N, Vicary F, et al. Motivations and incentives: exploring assistive technology service delivery from the perspectives of multiple stakeholders. In: Yih- Kuen J, Ray G, editors. *RESNA 2015: new frontiers in assistive technology.* Denver (CO): RESNA; 2015.
- [52] Layton N, Volkert A, Joyce R. ARATA/AFDO/OTA Breakfast Forum on Assistive Technology. Australian Assistive Technology Conference; 2018 November 15; Melbourne, Australia.

- [53] Layton N, Noonan M, O'Connor J. My assistive technology outcomes framework – a collaborative tool for AT users and their practitioners. Melbourne (Australia): AOPA; 2019.
- [54] Layton N, Thomson C, Noonan M. Consumer-defined outcomes: applying the assistive technology outcomes framework applied to wheeled mobility and seating. Melbourne (Australia): Oceania Seating Symposium; 2019.
- [55] Layton N, Doyle L, Volkert A. My Outcomes Framework: synthesising the evidence on valued outcomes into a set of user-led and policy-relevant tools. Paper presented at the Occupational Therapy Australia 28th National Conference and Exhibition; 2019 July 10; Sydney, Australia.
- [56] Keeney S, Hasson F, McKenna H. The Delphi technique in nursing and health research. Chichester (UK): Wiley- Blackwell; 2011. p. 1–17.
- [57] Ogbeifun E, Agwa-Ejon J, Mbohwa C, editors. The Delphi technique: a credible research methodology. Paper presented at the 2016 International Conference on Industrial Engineering and Operations Management; 2016 March 8–10; Kuala Lumpur, Malaysia.
- [58] Jünger S, Payne SA, Brine J, et al. Guidance on conducting and REporting DElphi studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliat Med.* 2017; 2017/09/0131(8):684–706.
- [59] Southern African Development Community - Towards a common future. 2012. [cited 2021 Sep 1]. Available from: <https://www.sadc.int/about-sadc>
- [60] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101.
- [61] Renzo A, Niels-Erik M, Evert-Jan H, et al. Service delivery systems for assistive technology in Europe: an AAAT E/EAST IN position paper. *Technol Disabil.* 2013;25(3):127–146.
- [62] World Health Organisation. Priority assistive products list. Geneva (Switzerland): World Health Organisation; 2017.
- [63] Boisselle A, Grajo L. They said: a global perspective on access to assistive technology. *The Open J Occup Ther.* 2018;6(3):2.
- [64] Berghs M. Practices and discourses of ubuntu: Implications for an African model of disability? *Afr J Disabil.* 2017;6:292.

Examining the Tactile Sign Language Used by and With the Deafblind in Ethiopia

Pawlos Kassu Abebe (PhD)

Addis Ababa University
pawlos.kassu@aau.edu.et

Abstract

Understanding the methods of communication used by the deafblind is a key in meeting almost all their needs. One of the communication methods used by and with the deafblind is a tactile sign language. The limited research available in the field, mostly in the tactile sign languages used in the Western part of the world, indicates that, among others, various forms of adaptations are needed to be made in order to make the visual sign language accessible to the deafblind. The aim of this study was to examine the tactile sign language used in Ethiopia in the light of existing research in the field. Identification of the adaptations made, the features of the visual sign language lost in the process of adaptations, the strategies adopted to compensate for the loss of the grammatical features of the visual sign language that can no longer be perceived and determining their impact on the communication process were the main focus of the study. A qualitative research method was employed. Data was collected through observation and interview from two deafblind signers and two interpreters of the deafblind which were recorded and analyzed. The result showed that the needed adaptations and modifications in the visual sign language were not made which rendered the communication ineffective and deprived the deafblind of the much needed information for survival uncovering the need for study on the Tactile sign languages used in Africa, a guideline for adaptations and a training for both the deafblind and their interpreters.

Introduction

This study examined the Tactile Sign language used by and with the deafblind in Ethiopia in light of existing findings in the field of Tactile Sign language research. The term 'deafblindness' refers to a combined hearing and vision loss. Although most individuals with deafblindness have some functional use of vision and hearing, the combination of losses greatly impairs the ability to gather auditory and visual information. This creates intensive communication and learning needs that cannot be met by programs designed solely for persons who are blind or have low vision, or

persons who are hard of hearing or deaf. The population of individuals living with deafblindness is an extremely diverse group. Very few individuals are both profoundly deaf and completely blind. The majority have varying degrees of residual hearing and vision.

Deafblind people use different methods of communication that suits their type of deafblindness. The choice of the communication methods depends on what they learned or acquired during childhood. One of the methods used by the deafblind who lost their vision after they developed visual sign language skill is a method where a listener place their hands on top of a speaker's hands to receive the signs. In this method a deafblind signer will follow a conversation by placing one or both hands on top of the hands of someone who is signing. The signs are signed into the Deaf-blind individual's hands. Many people with Usher Syndrome type I use this approach because they have been exposed to visual sign languages during childhood. Multiple names have been given to this form of communication which includes: "hands on", "tactile sign language" and "hand-under-hand signing". The name "Tactile sign language" is used to refer to the method in this study. Tactile sign languages are modified versions of Sign languages. It, therefore, has become a norm to name "Tactile sign language" after the visual sign used in each country such as tactile American Sign Language (Tactile ASL).

Sign language is a complex combination of facial expressions, mouth/lip shapes, hand and body movements, and finger spelling which needs vision to comprehend. Deaf or non-deaf, a person with a normal vision has little difficulty in learning and communicating with a Sign language. However, for a person with no or little vision, the ability to comprehend a sign language depended on several adaptations made to the sign language used. This adaptations mark the difference between visual Sign language and Tactile Sign language. With a growing number of deaf signers gradually becoming deafblind and switching into a tactile mode of signing as well as the growing awareness on the need for meeting the communication needs of the deafblind, Tactile Sign languages are becoming an area of interest within the field of Sign language linguistics. Studies are being conducted in Tactile Sign languages around the world with the aim of understanding its structure and enhance the communication skill of the deafblind and the provision of interpreting service to them. Already it has become clear that Tactile Sign languages used around the world are different, therefore, findings cannot be generalized. Each of them needs to be studied in their own terms thus this study.

The presentation below begins with a review of existing research in the field and moves to describe the methodology. It then presents and discusses the findings before providing conclusions and recommendations.

State of the art

Compared to other fields, research in Tactile Sign languages is relatively new. There is limited research in the area and they are mostly in the Tactile Sign languages used in the Western world. Tactile American Sign Language (TASL) has enjoyed wider attention among researches than any other Tactile Sign languages (e.g. Petronio 1986;

Collins & Petronio, 1998; Edwards, 2012, 2014b, 2014a, 2018; Haas, Fleetwood, & Ernest, 1995). One of the earliest researches by Petronio (1986) examined the linguistic features of Tactile ASL as used by fluent deafblind adults and reported that the deafblind adults are able to successfully use and understand ASL tactually when placing one hand on the back of the signer's hand. Subsequent research in tactile ASL, in the tactile Swedish Sign Language (SSL) (e.g. Mesch, 2001, 2013), tactile French Sign Language (e.g. Schwarz, 2004, 2009), tactile Norwegian Sign Language (e.g. Berge & Raanes, 2013; Mesch; Raanes & Berge, 2017), tactile Japanese Sign Language (e.g. Bono et al., 2018) and tactile Australian Sign Language (Auslan) (Willoughby et al., 2014) all revealed that with proper adaptation Tactile Sign languages could be the way out of darkness for the deafblind.

In their review of several researches on tactile sign languages Willoughby et al. (2018), observed that tactile signers may make use of a wide variety of hand and body positions for tracking the signing of their interlocutor, however, the preferred hand positions used for sign reception is not the same around the globe. They also found out that a deafblind signer can only participate in dyadic conversation. The findings on question formation suggest that tactile sign languages do not have clear-cut grammatical forms for marking questions in the same way that visual sign languages do. Rather, they are recruiting or developing a range of manual and discourse features to signal that the utterance is to be read as a question. When it comes to turn-taking these studies find the importance of contact and hand position in accomplishing turn-taking. The major turn yielding signal observed was returning the hands to rest position, but that turn yielding was also accomplished by a more general decrease in signing speed and the indexing of addressee at the end of a turn, with a held question (Haas, Fleetwood, & Ernest, 1995). In the same manner Mesch (2001) noted that hands are raised somewhat from this position in order to indicate hesitation and lowered somewhat (but not returned to rest) to signal turn change. The way deafblind signers give feedback is the most distinct feature of tactile sign languages as observed through Willoughby et al. (2018) review of several researches. To make up for the inability to access to their addressee's facial expressions, nodding and laughter the deafblind utilize a variety of conventionalized taps and squeezes which are unique to tactile signing. Using their thumb to give one or more taps on the signer's hand and YES-tapping (Mesch, 2001) are the most observed taps. In tactile ASL an one-fingered tap on the signers hand signals attentiveness to the message and a 10 four-fingered tap carries senses such as "OK", "Oh I see" and "I agree" (Collins and Petronio, 1998). These researchers noted that the speed and number of repetition given to taps subtly changes the meaning. Tactile signers might give feedback about whether an utterance has been understood through grip cues (Raanes, 2011). In conveying environmental information to deafblind signers make use of a range of communicative symbols and practices known as social haptic communication or 'haptics' were observed. These outside of standard tactile signing, includes, for example, by drawing the outline of a room on the back of a deafblind person in order to convey the location of doors, tables, etc. or where different people are sitting (Berge and Raanes, 2013). Visual sign languages make grammatical use of markers, such as facial expressions, eye gaze, and body posturing and head movement which are known as non-manual markers (NMMs). The information conveyed

by these markers is lost in the transition from the visual to the tactile modality, since they cannot be perceived by the addressee (this also leads to their gradual disappearance in the Deafblind signer (Lillo-Martin & Klima, 1990). Lillo-Martin & Klima also noted that the salient feature of Sign languages known as the use of space to convey information particularly, to establish reference is altered in Tactile Sign languages. In signed discourse, signers articulate some signs in the neutral space (roughly, the space in front of the torso) and the regions of space in which these signs are articulated are relevant to establish reference, however, such use is not observed among tactile sign language users.

Reed et al. (1995) reported that when Deafblind receivers misunderstood, the misunderstanding often occurred within the handshape parameter. This was supported in a research conducted by Collins and Petronio (1998). In standard ASL, a signer looks directly to the receiver while asking a wh-question, and thus, the receiver knows the question is specifically for them. However, Collins & Petronio, (1998) noted that in the tactile ASL, several wh-questions were preceded by the sign YOU directed toward the receiver even though "YOU" was not the subject or the object of the sentence. In the cases studied it appears that the sign YOU was a substitute for the signer's eye-gaze. The sign YOU gets the receiver's attention, and informs them something will be directed toward them. They also noted that in the use of Tactile Sign languages certain sign production parameters were changed due to the need for body contact or to the physical limitations of space. They observed a phonological assimilation occurred in the use of Tactile Sign language due to the necessity of the signers' proximity. Later research suggested that these adaptations result in grammatical variation. For instance in ASL adverbial morphemes occur on the face and are non-manual signals that the deafblind signer does not see. This requires the ASL signer to make a slight modification, from these "invisible" non-manual morphemes to a tactile morpheme. Collins (2004) investigated how the adverbial morphemes are represented in tactile American Sign language among adults with acquired deafblindness. He uncovered numerous tactile adaptations which include the semantic categories manner/degree, time, duration, frequency, purpose, place/ position/direction. He noted that adding signs to substitute head movement or facial expressions which could not be observed by the deafblind individual was observed. He also reported that singular and pluralism may be indicated by touching one time or many times or making a movement once or many times. Interrogative sentences may for instance be made by adding signs or with specific movements, hand and body positions. Collins identified the unique tactile features to be variations/ adaptations of visual sign language, which may be different from tactile language acquired as a first language. He concluded that grammatical variation exists between visual ASL and Tactile ASL.

There is, however, diverse opinion on whether Tactile Sign languages are natural of variations of the visual Sign languages used by the deaf. Most recent research suggests that there isn't a naturally occurring Tactile Sign language (Hart, 2010; Dammeyer et al., 2015). This is because the conditions for the emergence of a natural tactile language that will be passed to the next generation are very limited at the best (Dammeyer et al., 2015). According to them Tactile Sign languages are products of an effort aimed at making Visual Sign languages accessible to the deafblind. In Visual Sign language movement, location and hand shape are the main building blocks. In

Tactile Sign language the building blocks may include speed, acceleration, position relative to other body parts, muscle tension and pressure. Touching gently may have a different meaning than touching with force and muscle tension in shoulder and arm may have different semantic meaning than lack of muscle tension in shoulder and arm (Dammeyer et al., 2015). Supporting this Deuce & Rose (2019) also argued that Tactile Sign languages are results of adaptations to existing Sign languages and touch systems, which have been developed by people thinking about how to signal messages in a tactile way. Checchetto, et.al (2018) also noted that tactile Italian Sign language (LISt) they studied did not show the attributes of a natural language. However, they suggested that tactile languages have the potential of becoming complete grammatical systems, at least when they build on previous knowledge of a Visual Sign language. In contrary to these claims Edwards, (2014) argued that the observed changes in the structure of Tactile American Sign language (TASL) qualify the language to be labeled a new language. He examined a divergence in the sublexical structure of Visual American Sign language (VASL) and TASL and concluded that TASL is a language, not just a relay for VASL.

Checchetto, et al. (2018) compared Italian Sign language (LIS) and LISt to identify strategies adopted to compensate for the loss of the grammatical features of the visual language that can no longer be perceived. They argued that the transformation of LIS into LISt is constrained by grammatical principles, rather than reflecting communication strategies that in principle might compensate for the visual loss equally well. Certain innovations are introduced to carry over the grammatical features of LIS to LISt. Even when LISt undergoes processes that make it diverge from LIS.

Regarding sitting positions Mesch (2001), discussed two basic positions which tactile signers can adopt: the monologue position and the dialogue position. In the dialogue position, the two signers sit across from each other and the dominant hand of each signer is under the non-dominant hand of the other signer. The dominant hand articulates the sign while the non-dominant one receives it by detecting the handshape, the orientation and the movement path of the dominant hand of the interlocutor. This allows signers to take turns rapidly. In the monologue position, which is typically used when one person talks to another for an extended time, each signer uses both hands to articulate signs or to receive them.

An interesting observation made in a number research (e.g. Edwards, 2014; Willoughby et al., 2014; Collins, 2004; Mesch, 1998) is that just as Visual Sign languages used among the deaf around the world differ per country, Tactile Sign languages also differ from country to country. This suggests that the findings in the Tactile Sign languages of the Western world cannot be automatically applied to the Tactile Sign languages, for instance, used in Africa. Unfortunately, searches for study in the Tactile Sign languages used in Africa revealed no result. The objective of this research, therefore, is to examine the tactile sign Tactile Sign language used by and with the deafblind signers in Ethiopia, who acquired EthSL before they lost their sight, in light of the above observations.

Statement of the problem

Research indicates adaptations and modification of the Visual Sign languages is necessary to make them accessible to the deafblind. In the process some of the features of the Visual Sign languages are lost in Tactile Sign languages due to the loss of vision and a new set of strategies are employed to compensate for the lost features.

A tactile form of Ethiopian Sign language (EthSL) is used by and with the deafblind in Ethiopia. However, this tactile sign language is not studied, therefore, nothing is known of the adaptations and modifications made or needed, the features lost in the process of the adaptations and modifications, how those adaptations and modifications impact the message, if the interpreters for the deafblind are aware of the needed adaptations and modifications to be made etc. Understanding all these issues is crucial to providing the overall support the deafblind needs including education and interpretation services as well as developing the tactile sign language.

Among other the study aims to answer the following key research questions:

1. What are the adaptations and modification the tactile sign language used in Ethiopia has made to the visual EthSL?
2. What are those features of the visual EthSL lost in the process of adaptations and modifications into tactile form?
3. What are strategies adopted to compensate for the loss of the grammatical features of the visual EthSL that can no longer be perceived?
4. How does the adaptations and modification impact the communication?

Objectives

The general objective of this study was to examine the Tactile Sign language used by and with deafblind in Ethiopia, who already have acquired EthSL before becoming deafblind, in light of existing research in the field. The specific objectives were:

1. To identify the adaptations and modifications made to the visual EthSL to use it in a tactile form.
2. To find out the features of the visual EthSL lost in the process of adaptations and modifications.
3. To identify the strategies adopted to compensate for the loss of the grammatical features of the visual EthSL that can no longer be perceived.
4. To determine the way the adaptations and modifications impacted the communication.

Methodology

A qualitative research method was employed for this research. The qualitative research method is geared toward creating a complete and detailed description of an observation as a researcher and offers contextualization and interpretation of the data gathered. This research method is subjective and requires a smaller number of carefully chosen respondents such as this.

Participants

Limited informants were involved in this study due to the fear of body contact imposed by COVID-19 restrictions throughout the duration of the study. Two deafblind, a woman and a man, and two Deaf interpreters both participated in this study. They were chosen for the study because they were among the few most known deafblind adults using Tactile Sign language and were willing to take part in this study. As it is typical among deafblind signers the two deafblind participants were adults who were pre-lingual deaf and learnt visual EthSL as children before losing their sight due to degenerative conditions. Although they do not know what led to their gradual loss of vision, from observation and their description, it looked both of them suffered Usher Syndrome Type 1. Both have some residual vision enough to detect light which, however, did not enable them to visually perceive EthSL. They totally depend on tactile sign language for all communication. The two deaf interpreters were chosen for the study because they were pre-lingual deaf and have known the deafblind participants while they were still in deaf schools and use visual sign language fluently. They have interpreted for the two deafblind participants in the church setting for more than ten years and considered themselves most competent interpreters of the deafblind.

Data

Observational method and interview were employed to collect data. Observational method allows researchers to collect data based on their view of the behavior and characteristics of the respondent, with the respondents themselves not directly having an input. The observation was done in two parts, recorded on video and analyzed thoroughly afterwards. The first part of the observation was the interaction between the deafblind and their interpreters during a lesson. The second is in the process of interviewing conducted by the interpreters. Analysis of video observation has been a frequently used methodological approach in researching the Tactile Sign languages and was therefore, the best available methodological choice for this study. Both the deafblind and the interpreters were interviewed. The aim of the interview for the deafblind was to assess their comprehension level while the aim of the interview to the interpreters was to assess their understanding of the “how”s of Tactile Sign languages and the observations made.

Procedure

The researcher met with the deafblind and deaf interpreters in person and explained the research and its objectives as well as the procedures to be followed in details. Consent was obtained after numerous discussions to address concerns related to COVID-19 restrictions and agree on safeguarding measures. One of the agreements was to keep the identity of both the deafblind and their interpreters anonymous to avoid any legal implication in case of being exposed to COVID-19.

The deafblind participants are regular church goers where most of their interactions happened. The two interpreters also worked with the deafblind in church for more than ten years. Church setting, therefore, was considered to be the most familiar setting for the research.

During a weekly bible study program for deaf and deafblind members in the church, the deafblind sat side by side with their respective interpreters putting their left hands on top of the active hand of the interpreters because this was how they always sat. The researcher, being deaf and fluent user of visual EthSL as well as one of the teachers in the church taught a familiar biblical lesson for thirty minutes without altering the normal speed and procedure. The interaction of the deafblind with their interpreters during the lesson was recorded. After the lesson the deafblind were interviewed. During the interview the deafblind and their interpreters were made to sit face to face. The deafblind were asked to retell the lesson taught as well as asked to share their personal experience in life. After the prepared questions were asked the interpreters were encouraged to ask spontaneous questions to encourage more interactions. The questions were passed to the deafblind tactually while they provided their replies non-tactually. The interaction was recorded.

The interview with the interpreters conducted by the researcher in visual EthSL and not recorded. The open ended interview questions for the interpreters focused on assessing their experience of interpreting for the deafblind and their knowledge of the modifications and adaptations needed to be made in the visual EthSL as well as the strategies to be adopted to compensate for the loss of the grammatical features of the visual EthSL. A total of 71.15 minutes video recordings were obtained and analyzed.

The researcher studied the video in light of the findings in an already researched Tactile Sign languages, searching for any possible adaptations, modifications, strategies and compensations for losses.

Results

Adaptions and modification made to the visual EthSL when used in tactile form

Much the adaptations reported in other research were not observed in this study. The deafblind informants exhibited a fair knowledge of the visual EthSL with its complete components including NMFs. No significant adaptation was observed in visual

EthSL signed by the deafblind informants when they signed none tactually except the narrowing of the signing space.

Few adaptations were observed to the visual EthSL when the interpreters signed tactually. One of them was allowing the deafblind to put their hands on the dominant hand and follow the sign. The other visible adaptation and modification made is in the signing space of the signs with no body contact such as the sign YOU. The sign which is made in the air is modified to touching the deafblind and themselves with the tip of their pointing finger when signing YOU and ME/I. The functions of the sign YOU also were adapted to play partial roles of eye-gaze in visual EthSL as well as a way of getting the receiver's attention. A bit of modification also was observed in indexing or pointing. Indexing or pointing was done with the active hand held by the deafblind.

Despite multiple visible needs for adaptations and modifications the interpreters did not make them. The non-dominant hand of the interpreters was moving normally and no adaptation was made by the interpreters to make it accessible to the deafblind. NMFs, pointing and question marks were freely used by the interpreters just as they are used in the visual EthSL. During the 30 minutes lesson the interpreters were not seen making efforts to ensure the deafblind were following and the message is passed properly. The deafblind also showed no signal of any type, request for repeating or clarification. However, during the interview session when the deafblind failed to comprehend the question mark on the face, a manual question mark was used. Surprisingly in few cases the deafblind understood the manual question mark, possibly from the hand movement they were holding, when it was repeated to them two or three times. It was not clear if it was a strategy or an adaptation but during the interview session the interpreters were observed multiple times randomly holding the signs and NMFs still as if giving time to the deafblind to assimilate/recognize the signs and the NMFs.

In the interview the interpreters admitted that they did not know what to adapt and modify in the visual EthSL and how to adapt and modify as well. They thought the only adaptation or modification needed to be made was allowing the deafblind to hold their hands and slow the speed as well as repeat the sign, phrase or sentences as needed. The interpreters also were not aware of the various signals the deafblind make during the interpreting process as well as how to respond to those signals. They also claimed, but not observed, that they make adaptations whenever there is a need for such adaptations and though the deafblind were smart enough to understand the random adaptations and modification they spontaneously make. They have also never discussed the preferred hand and body positions with the deafblind and did not know the preference of the deafblind partners in the communication.

The features of the visual EthSL lost in the process of adaptations and modifications into a tactile form

Throughout the lesson and the interview session the interpreters kept showing the features of visual EthSL without visible adaptations depriving the researcher of the

opportunity to assess the features of the visual EthSL lost in the process of adaptations and modifications into tactile form. The roles of eye gaze and pointing were completely lost as the deafblind were not able to observe them.

The interview with the interpreters revealed lack of knowledge on how the transition from visual EthSL to tactile signing impacts the grammatical features of the visual EthSL. They were not able to point out the features that could be lost nor were they observed during the interaction with the deafblind.

The strategies adopted to compensate for the loss of the grammatical features of the visual EthSL that can no longer be perceived.

The interpreters were not observed using any tangible strategy to compensate for the loss of grammatical features of the visual EthSL that can no longer be perceived. In fact, they keep showing features such as NMFs even though the deafblind were not in a position to perceive them. They however, were observed repeating signs, phrases and sentences, sometimes up to eight times to help the deafblind understand the message. While repeating the phrase or sentences they rephrase the phrase and sentences and change signs to another sign closer in meaning.

Letting the deafblind hold their hands was one of the strategies adopted to aid understanding, though not to compensate for the loss of the grammatical features.

In few cases the turn taking signals observed by Haas et al, (1995) and Mesch (2001) where observed. The deafblind raised or returned to rest position the non-dominant hand as well as indexed the interpreters at the end of a turn. However, the interpreters did not react to the signals appropriately even though they also indexed the deafblind when it was their turn.

The impact of the adaption and modification made on the communication

The communication was in most part ineffective. The communication was impacted negatively not by the modifications and adaptations made but by the lack them. The deafblind failed to answer almost all the questions drawn from the lesson even after the questions were repeated to them up to eight times in multiple sign orders. They also needed the interview questions to be repeated, at times eight times, before they could partially comprehend and respond to.

Discussion

This study revealed a number of interesting issues. Among others it has reconfirmed that the loss of sight alone does not automatically result in the loss of the deaf signers' expressive skill. Both informants possessed good EthSL expressive skill however, the communication observed was ineffective. The unmatched level of the expressive and receptive skill of the deafblind informants indicate the difficulty they faced in accessing the signs used by the interpreters due to lack of proper modification to the

signs. As noted by Willoughby et al. (2018) the move from a visual to tactile mode of perception necessitates a number of adaptations in the way a message are communicated. Without such adaptations the communication is bound to be ineffective as observed in this research. Both the deafblind informants and the interpreters seem to lack the ability to make these most important modifications and adaptations. Checchetto, et.al (2018:67) noted that “When the transition to the tactile modality results in loss of information, we might expect tactile signers to make up for this loss by modifying some pre-existing manual items, or by introducing novel manual signs (or by combining some of these options)”. This suggests, on one hand accomplishing this task doesn’t seem to come naturally. On the other hand making modifications rests on the shoulders of both the deafblind and the interpreter. Since both the deafblind and the interpreters were not empowered to undertake this complex task of either modifying pre-existing manual items or introducing novel manual signs as well as not aware of their individual responsibilities the most important task of adapting and modifying the visual EthSL to make it accessible to the deafblind was left undone which in turn impaired the communication.

The inability of the deafblind to detect the handshapes seems to be one of the factors that contributed to the lack of understanding in this study. The way the interpreters let the deafblind hold their hands did not seem convenient for the deafblind to differentiate handshapes properly and limited their understanding of the message. As Reed et al. (1995) noted when deafblind receivers misunderstood, the misunderstanding often occurred within the handshape parameter. This seems the case here.

The interpreters in this study did well in their attempt at making messages accessible by changing signs and rephrasing phrases and sentences. Checchetto, et.al (2018) had observed a similar approach in their study of LIS where they noted that whenever a LIS construction stops being perceivable in LIS a LIS construction that can convey the same or a similar meaning is systematically employed. The shortcomings observed in this study were that the interpreters did little to increase the accessibility of the signs to the deafblind by making proper modifications before moving to explore other available alternatives to pass the message.

In Sign Language, eye gazing serves a variety of functions. It can regulate turn taking and mark constituent boundaries. Eye gazing is also frequently used to repair or monitor utterances and to direct the addressee’s attention (Lucas, 1998). However, in the adaptation made in this study they served only to regulate turn taking. Since no strategies were adopted to compensate for the loss of the other grammatical features the communication was at best incomplete.

In their analysis of a conversation between two users of tactile ASL, Haas et al’s (1995) noted that the two interlocutors use a wide variety of structures for marking polar questions, and that they employ these structures at different rates. However in a later study but a more broad study in tactile ASL, Collins and Petronio (1998) noted that signers in their study formed polar questions with the question mark sign. In agreement with observation of Collins and Petronio the interpreters in this study used question mark sign to form polar questions. In most cases the deafblind

understood the marks possibly from the movement of the hands. This seems to align with the observation of Willoughby et al., (2018) that tactile sign languages do not have clear-cut grammatical forms for marking questions in the same way that visual sign languages do.

In few cases the turn taking signals observed by Haas, Fleetwood, & Ernest,1995; Mesch, 2001 where the non-dominant hands returning to rest position, indexing of addressee at the end of a turn, raising the non-dominant hands also were observed. However, the interpreters failed to notice them or did not seem to understand the meanings of the signals.

The interpreters interviewed for this study believed that the random modification they made to the EthSL while interpreting for the deafblind informants were understood by the deafblind. However, as Checchetto et al. (2018) noted such beliefs are unfounded and communicative device invented by interpreters actually never used by deafblind people, therefore is never understood. The interpreters did not give it a thought that deafblind use an alternative strategy which is not present in the visual sign language but is attested in other sign and spoken languages. The interview with the interpreters revealed lack of knowledge on how the transition from visual EthSL to tactile signing impacts the grammatical features of the visual EthSL.

Conclusions

This research has its own limitations. Both the number of participants and the single setting is limited. Using more participants and making the assessment at multiple settings could have shade more light and could have provided better opportunities to come across to more adaptations and modifications as well as strategies not observed in this study. However, regardless of its limitations it has uncovered that many of the adaptations observed in other tactile sign languages were not made in tactile sign language studied. The interpreters did not make the needed adaptations to the expected level nor employed adequate strategies to make up for the loss. The deafblind are also not observed playing an active role in providing feedbacks and in modifying the visual EthSL to suit their needs. The tasks left undone clearly impacted the communication negatively. It also made clear that the absence of proper adaptations and modifications impairs communication and restricts or hinders the accessibility of the message to the deafblind. From all the observations and the unmatched expressive and receptive skills of the deafblind participants it might be in order to conclude that the tactile sign language used by the interpreters studied falls short of a description of a tactile sign language. It is evident that there is a lot to be done to bring the visual Ethiopian Sign language to the level of Tactual Ethiopian Sign language.

Recommendations

1. Providing effective services to the deafblind depends on the effectiveness of the communication method used. Therefore, efforts should be encouraged for

the study of all tactile sign languages in Africa in particular and the world at large in general.

2. Based on the research available a guideline on how to adapt and modify visual sign languages into tactile sign languages should be designed.
3. Adapting and modifying visual sign languages into tactile sign languages require expertise and a team work between the deafblind and deafblind interpreters. To achieve this both the deafblind and the deafblind interpreters need to be empowered through formal trainings.
4. The skill and awareness level of deafblind interpreters is inadequate therefore extensive training programs are urgently needed.

Acknowledgments

This study was made possible with a financial grant from Deafblind International (DbI) through its initiative African Research Initiative (ARI).

To Mr. Mirko Baur and Dr Daniel Dogbe who reviewed this study and provided constructive feedback.

References

Berge, S. S., & Raanes, E. (2013). Coordinating the chain of utterances: An analysis of communicative flow and turn taking in an interpreted group dialogue for deaf-blind persons. *Sign Language Studies*, 13(3), 350–371. <https://doi.org/10.1353/sls.2013.000>

Bono, M., Sakaida, R., Makino, R., Okada, T., Kikuchi, K., Cibulka, M., & Fukushima, S. (2018). Tactile Japanese Sign Language and Finger Braille: An Example of Data Collection for Minority Languages in Japan. Presented at the 8th Workshop on the Representation & Processing of Sign Languages: Involving the Language Community, Miyazaki. Retrieved from http://lrecconf.org/workshops/lrec2018/W1/pdf/18027_W1.pdf

Checchetto, A. & Geraci, C. & Cecchetto, C. & Zucchi, S., (2018) "The language instinct in extreme circumstances: The transition to tactile Italian Sign Language (LISt) by Deafblind signers", *Glossa: a journal of general linguistics* 3(1), p.66. doi: <https://doi.org/10.5334/gjgl.357>

Collins, S., (2004). Adverbial Morphemes in tactile American sign language. Cincinnati, OH: Graduate College of Union Institute and University.

Collins S. & Petronio, K., (1998). What Happens in Tactile ASL? In: C. Lucas (ed.) *Pinky extension and eye gaze language use in deaf communities*. Washington, WA: Gallaudet University Press pp. 18-37.

Dammeyer, J., Nielsen, A., Strøm, E., Hender, O & Eiriksdóttir, V. K. (2015). A case study of Tactile Language and its Possible Structure: A Tentative Outline to Study Tactile Language Systems among Children with Congenital Deafblindness. *Journal of Communication Disorders, Deaf Studies and Hearing Aids*. Vol 3:2 (pp.1-7).

Deuce, G. & Rose, S. (2019). 'Sign Acquisition in children who are deafblind'. In Grove, N. & Launonen, K. (Eds) 'Manual Sign Acquisition in children with Developmental Disabilities'. Nova Publishers: USA.

Edwards, T. (2012). "Sensing the rhythms of everyday life: Temporal integration and tactile translation in the Seattle Deaf-Blind community" *Language in Society* 41(1): 29–71.

Edwards, T. (2014a). From compensation to integration: Effects of the pro-tactile movement on the sublexical structure of Tactile American Sign Language. *Journal of Pragmatics*, 69, 22–41. <https://doi.org/10.1016/j.pragma.2014.05.005> 17

Edwards, T. (2014b). *Language Emergence in the Seattle DeafBlind Community*. University of California, Berkeley. Retrieved from <http://search.proquest.com/openview/63cb352317bb90097011b9a64d105b52/1?pqorigsite=gscholar&cbl=1875>

Frankel, M.A. (2002) Deaf-Blind Interpreting: Interpreters' Use of Negation in Tactile American Sign Language, *Sign Language Studies* 2(2): 169-181.

Hart, P., (2010). *Moving Beyond the Common Touchpoint – Discovering Language with congenitally deafblind people*. (Doctor of Philosophy, University of Dundee). Retrieved from: http://discovery.dundee.ac.uk/portal/files/1193330/Hart_phd_2010.pdf accessed on 09/04/2018.

Haas, C., Fleetwood, E., & Ernest, M. (1995). An analysis of ASL Variation within Deaf-Blind-DeafBlind interaction: Question forms, backchanneling, and turn taking. In *School of Communication Student Forum* (pp. 103–40).

Lillo–Martin, D. & Klima, E. S. (1990). Pointing out differences: ASL pronouns in syntactic theory. In S. D. Fischer & P. Siple (eds.), *Theoretical issues in sign language research*. Volume 1: Linguistics, 191–210. Chicago: University of Chicago Press.

Lucas, C. (1998). *Pinky extension and eye gaze: Language use in Deaf communities* (Vol. 4). Gallaudet University Press.

Mesch, J., (2000). Tactile Swedish Sign Language: Turn Taking in Conversations of People Who Are Deaf and Blind. In M. Metzger (Ed.), *Bilingualism and Identity in Deaf Communities*. Washington, WA: Gallaudet University Press pp. 187-203.

Mesch, J., (2001). *Tactile Swedish Sign Language – turn taking and questions in signed conversations of deaf-blind people*. Hamburg, Germany: Signum-Verlag.

Mesch, J., (2013). Tactile signing with one-handed perception. *Sign Language Studies* 13(2): 238-263. 7. O'Brien S, Steffen C (1996) Tactile ASL: ASL as Used by Deaf-Blind

Persons. Gallaudet University Communication Forum. Volume 5. Washington, WA: Gallaudet University Press.

Petronio, K. (1986). Some Features of Tactile ASL. Unpublished manuscript. Washington, DC: Gallaudet University.

Raanes, E., (2006). Å gripe inntrykk og uttrykk. Interaksjon og meningsdanning i døvblindes samtaler. [To catch impression and expression. Interaction and meaning making in conversations of people with deafblindness.] Trondheim, Norway: NTNU The Norwegian Technical University, Department of Language and Communication.

Raanes, E., & Berge, S. S., (2017). Sign language interpreters' use of haptic signs in interpreted meetings with deafblind persons. *Journal of Pragmatics*, 107, 91–104. <https://doi.org/10.1016/j.pragma.2016.09.013>

Reed, C. M., Delhorne, L. A., Durlach, N. I., & Fischer, S. D. (1995). A study of the tactual reception of sign language. *Journal of Speech and Hearing Research*, 38(2), 477–489.

Schwarz, S. (2004). *Éléments pour une analyse de la langue des signes tactile pratiquée par les personnes sourdes-aveugles* (PhD diss.). Université Paris VIII - St Denis Département de Sciences du Langage.

Schwarz, S. (2009). *Stratégies de synchronisation interactionnelle: alternance conversationnelle et rétroaction en cours de discours chez des locuteurs sourdaveugles pratiquant la Langue des Signes Française tactile* (Interactional synchronization strategies: alternating and conversational communication and feedback signals in French tactile sign language). (Dissertation. Sciences du langage). Université PARIS 8, Paris

Willoughby, L., Manns, H., Iwasaki, S., & Bartlett, M. (2014). Misunderstanding and repair in Tactile Auslan. *Sign Language Studies*, 14(4), 419–443. <https://doi.org/10.1353/sls.2014.0014>

Willoughby, L. J. V., Iwasaki, S., Bartlett, M. J., & Manns, H. J. (2018). Tactile sign languages. In J-O. Östman, & J. Verschueren (Eds.), *Handbook of Pragmatics: 21st Annual Installment* (pp. 239-258). John Benjamins Publishing Company.

Management Strategies of Children With Deafblindness in Special Education Schools in Lusaka, Zambia

Rachel Muuma Chomba

Munali Girls Secondary School, Lusaka, Zambia

Copyright

All rights reserved. No part of this dissertation may be reproduced, stored in any retrieval system, transmitted in any form or by any means, electronic, recording, mechanical, photocopying or otherwise without prior permission in writing from the Author.

© 2021, Rachel Muuma Chomba

Dedication

This work is dedicated to my loving sons Takondwa Jayden and Taizya and my beloved nephew Marcus. It is my prayer that Jehovah exalts you to reach greater heights than I have done.

Acknowledgements

I would like to acknowledge and give my gratitude to my ever dedicated supervisor Mr Victor Locoro for his guidance, openness and prompt support in the process of this research.

I wish to also give gratitude to Deaf Blind International for sponsoring this this research. Above all, I thank the Almighty God for rendering an opportunity and good health to carry out this study.

Abstract

The study investigated management of children with Deaf-Blindness in primary special schools and units of Lusaka District. It also examined parental involvement in the management of learners with deaf-blindness and the challenges faced by head teachers, teachers and parents in the management of children with deaf-blindness in school.

A Descriptive study design was used with a qualitative research approach. 26 participants were drawn from six selected primary schools of Lusaka district. The sample consisted of 2 head teachers, 12 teachers and 12 parents of learners

with deaf-blindness who were sampled purposively. The data was collected using interviews and observation and was analyzed thematically using description.

The findings revealed that management of children with deaf-blindness in primary special schools and units is dependent on the teachers understanding of the characteristics of the disability and is highly individualized. Head teachers and teachers from the visited schools provided various educational and social management strategies that are used to meet the needs of learners. Even though strategies were given, it was acknowledged by the head teachers and teachers that there were not fully trained to meet the needs of learners with deaf-blindness. This was attributed to poor pre-service training and low knowledge levels on deaf-blindness. The study established that children with mild to moderate deaf-blindness progress to higher educational levels whilst those with severe sensory loss are mainly taught Activities of Daily Living. Instructional strategies are individual based and all teachers mentioned the use of Individualized Education Plans.

CHAPTER ONE

INTRODUCTION

1.0 Overview

This chapter discusses the background of the study, statement of the problem, purpose of the study, research objectives, research questions, significance of the study, limitations of the study, theoretical framework and definition of terms.

1.1 Background

Increasing research and concern on disabilities in developed countries has led to early diagnosis of disabilities which has seen appropriate intervention and services provided to learners with special education needs in special, inclusive, mainstream and regular schools. The estimated prevalence rate of children with disabilities according to World Health Organization in the World Report on Disability (2015) of children aged 0-14 years experiencing moderate to severe stands at 93million (5.1%) and 13 million (0.7%) with severe difficulties. Additionally, the National Centre for Education Statistics in the U.S department of education (2015) estimated in 2014-2015 the number of children and youth aged 3-21 receiving special education and services at 6.6 million (13%) of all public school students. Deaf-blindness is defined as concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness (Alsop, L. (Ed.), 2002). Some people are Deaf-blind from birth. Others may be born deaf or hard-of-hearing and become blind or visually impaired later in life. Vision and hearing are the primary senses through which we collect information. The normal development of a child is affected when

these channels for receiving information are impaired or not functioning (McInnes, J. M., & Treffry, J. A., 1993). Individuals with deaf-blindness are left with option of accessing information through tactile modality while those who acquire it in later life are left with the option of tactile and signing to access the environment.

Deaf-blindness is a low-incidence disability. There is some data available on the prevalence deaf-blindness in countries like the United States and the United Kingdom, but estimated numbers of persons living with deaf-blindness in many parts of the world are unavailable. In Zambia, unfortunately, no survey has been done to establish the number of individuals living with deaf-blindness. However some special schools have received learners living with the disability.

The population of individuals living with deaf-blindness is an extremely diverse group. Very few individuals are both profoundly deaf and completely blind. The majority have varying degrees of residual hearing and vision. For example, one person may have a severe hearing loss in combination with a level of residual vision that enables the use of close-vision sign language and the ability to read large, bold print. Another may be able to hear speech with the use of hearing aids and have night blindness as well as a restricted visual field. Deaf-blindness is a unique, complex disability and, as earlier noted, the population of individuals living with deaf-blindness is extremely diverse, with each individual having specific characteristics, strengths, and needs. Consequently, personnel who work with this population need an array of knowledge and skills.

Therefore, educators who work with individuals who are Deaf-blind have a unique challenge to ensure that the person has access to valuable information needed for their survival. It is against this background that the researcher embarked on research of the management strategies used to address the needs of learners with deaf-blindness in schools.

1.2 Statement of the problem

The combination of simultaneous hearing and visual impairment has significant consequences for many crucial aspects of life, including communication, learning, mobility, social and emotional development, and access to information and one's surroundings. Despite increasing awareness of the needs and potential of persons living with deaf-blindness, support and specialist services are still inadequate. As a relatively small population, with complex and diverse needs, they are often one of the last served (Riggio, M. & McLetchie, B. (Eds.), 2008). Services to assist persons living with deaf-blindness are frequently the last to be developed, particularly in economies that struggle to meet the needs of persons without disabilities and those with single or mild disabilities. Although there has been an increased awareness on special education among education practitioners, limited research has been done on the education of deaf-blind children. What is not known are the management strategies used to address the needs of learners with deaf-blindness in schools. Hence the need for the present study.

1.3 Purpose of the study

The purpose of the study was to investigate the management strategies employed on learners with Deaf-blindness in schools.

1.4 Specific Objectives

The study was be guided by the following objectives

1. To determine the management strategies used in meeting the needs of learners with deaf-blindness in schools.
2. To establish parental involvement in the management strategies of learners with deaf-blindness
3. To establish challenges faced in the management strategies of learners with deaf-blindness.

1.5 Research Questions

The study was guided by the following questions;

1. What strategies do head teachers and teachers use in the management of learners with Deaf-blindness?
2. How are parents involved in the management of their children with Deaf-blindness in schools?
3. What challenges are faced in the management of children with Deaf-blindness in school?

1.6 Significance of the study

The study was an attempt to bring awareness of Deaf-blindness in Zambia and Africa as a category of special education. It is hoped that the study will help improve delivery and quality of education provided to learners with Deaf-blindness and avail management strategies to teachers in schools who will be helped in catering for deaf-blind learners and their challenges will be discovered as information will be disseminated to the Special Education Department. It is further hoped that the study will benefit Deaf-blind learners as management strategies and involvement of their parents will be discussed.

1.7 Theoretical framework

The study was guided by the Theory of Mind (ToM). The proponents of the theory are a series of researchers and psychologists including Wimmer and Perner (1983) who popularized the theory. The theory of mind describes a difficulty someone has with perspective taking which referred to as "mind-blindness". ToM is fundamental to virtually every aspect of our mature social life: We could not properly communicate,

cooperate, compete, or engage in any other ways with other people if we did not constantly monitor how they view the world, what they know, want, and feel, and what they are up to. Due to this fundamental importance to our everyday life.

Since children with deaf-blindness are impaired both visually and auditory, they find the immediate social environment unpredictable and incomprehensible. Thus understanding the theory of mind of a deaf-blind child is important when coming up with management strategies that meet their needs. Frith & Frith, (2005) note that through having a Theory of Mind we can recognize that another person's knowledge is different from our own and we can manipulate other people's behaviour by manipulating their beliefs. Social cognition is at the heart of the child's ability to interact and learn from other people, therefore, basis of this crucial ability lies in the development of the theory of mind and research shows that the theory of mind development has consequences for children's social functioning and school success (Astington & Jenkins, 2008).

1.8 Limitations of the study

The study was conducted only in selected special schools and units of Lusaka hence; the results cannot be generalized to other schools in Zambia. In addition, the study was conducted at the time of a global epidemic Covid-19.

1.9 Delimitations of the study

The study covered head teachers, teachers and parents with children with Deaf-blindness from Special Education Schools and Units of Lusaka District for the convenience of the researcher as Lusaka district has more Special schools and Units with children with deaf-blindness enrolled in schools. Even though contact with respondents was minimal the researcher, with the help of modern technology, was able to gather data through emails, text messages, video and voice calls to ensure safety during the Covid-19 pandemic.

1.10 Definition of terms

Deaf refers to a condition where a person is unable to use their sense of hearing or hearing impairment

Blindness refers to inability for one to use their sense of perception or visual impairment

Deaf-Blindness refers to concomitant hearing and visual impairments

Management refers to how the learners with deaf-blindness are handled, taught and how the deficit areas of social interaction, communication and behaviours are fostered.

Management Strategies refers to plans or approaches used to teach and promote social, communication and behavioural development of deaf-blind learners

Parental Involvement implies parent's participation in school related activities of their child.

Social Interaction refers to the ability of children with deaf-blindness to relate interact and play with peers.

Special School an established institution for children with special educational needs

Special Unit is a class in a given mainstream school meant for children with special educational needs

1.11 Summary

The above chapter gave the background of the study, statement of the problem, purpose of the study, research objectives and questions and the significance of the study. It further presented the theoretical framework, limitations and delimitations of the study and the definition of terms used in the study. Therefore the next chapter focused on reviewing literature that is relevant to the study.

CHAPTER TWO LITERATURE REVIEW

2.0 Introduction

This chapter reviews literature on the management of deaf-blind learners by first outlining the characteristics of deaf-blindness, the academic, social and behavioural domains, parental involvement in the education of children with deaf-blindness and the challenges that teachers face in educating learners with deaf-blindness.

2.1 Characteristics of children with Deaf-blindness

The term 'deaf-blindness' refers to combined hearing and vision loss. Although most individuals with deaf-blindness have some functional use of vision and hearing, the combination of losses greatly impairs the ability to gather auditory and visual information. This creates intensive communication and learning needs that cannot be met by programmes designed solely for persons who are blind or have low vision, or persons who are hard of hearing or deaf (Alsop, L. (Ed.), (2002). The distance senses of hearing and vision enable individuals to receive information about the world beyond their reach. They are the main avenues for communication, learning, and socialization. Individually, each sense can compensate for the loss or diminished capacity of the other, to some extent. However, the combination of simultaneous hearing and visual impairment has significant consequences for many crucial aspects of life, including communication, learning, mobility, social and emotional development, and access to information and one's surroundings (Brown, D., 2008).

There are many causes of deaf-blindness. People who are deaf-blind differ in their degree of vision and hearing loss and in the age of onset of deaf-blindness, language

development, communication mode, and level of independence. With this functional diversity among persons who are deaf-blind, it is important to identify the needs of this population at the individual level. People who are deaf-blind can be classified into at least two groups: those who are congenitally deaf-blind, who experienced the onset of both hearing and visual impairment from birth to age 2 (Munroe, 2001), and those with acquired deaf-blindness, whose onset was later in life. Combinations of visual and hearing impairment are caused by a number of heterogeneous diseases and disorders. Visual and hearing impairment is the most common dual sensory impairment and 30 percent of children with hearing impairment have been found to have visual impairment (Nikolopoulos et al 2006). Pre-lingual deaf-blindness is extremely rare. (1 in 10.000) (Moller, C. 2007). Genetic syndromes, premature birth, congenital virus infections, are the most common causes. At least 20 different genetic syndromes are known to cause pre-lingual deaf-blindness. Some of which have been genetically identified (Moller, C. 2007). The rarity of these conditions and difficulties in assessment increase the risk of wrong diagnosis, which also may be "hidden" due to other dysfunctions and, thus attributed to other conditions (McInnes & Treffry, 1982; Moller, C. 2007). Developing severe visual and hearing impairment (post-lingual deaf-blindness) later in life is also rare. The etiology of post-lingual deaf-blindness is as in pre-lingual most often genetic. More than 50 hereditary syndromes are known to cause acquired deaf-blindness (Moller, C. 2007). Common causes of congenital deaf-blindness include intrauterine infections (like congenital rubella); congenital brain damage; and chromosomal abnormalities, such as CHARGE syndrome (Munroe, 2001; Watters, Owen, & Munroe, 2004). Acquired deaf-blindness can also be caused by genetically inherited disorders (such as Usher syndrome), as well as aging, postnatal or early childhood infections, and acquired brain injury (Munroe, 2001). Individuals living with deaf-blindness may experience:

- isolation;
- limited opportunities to communicate with others and interact with their surroundings in a meaningful way;
- difficulty establishing and maintaining interpersonal relationships;
- very limited number and variety of life experiences, including social interactions;
- limited opportunities for the development of concepts related to the environment in which a person lives which are necessary to understand and make sense of the world (i.e. people/places/things have names, events/things happen in a certain order, things come from/are kept somewhere and so on);
- limited access to information needed to anticipate future events or the results of one's actions;
- deprivation of many of the most basic motivations and instincts to explore and learn, function, and engage with the world;

- higher likelihood of being mislabeled as developmentally or intellectually disabled, emotionally disturbed, or autistic;
- increased vulnerability to abuse, including sexual abuse and associated consequences, such as HIV and AIDS, other sexually transmitted diseases, unwanted pregnancies, and post-traumatic stress disorder;
- medical problems that can lead to serious developmental delays and further sensory and other impairments.

2.2 Management of children with Deaf-blindness

Educational management

Every child with a disability has the right to education and different reforms and laws have been passed to enable children with disabilities access meaningful education in various countries worldwide. In Zambia, the Persons with Disability Act (2012) safeguards the right of children with disabilities in public schools to education and access to special education and equipment in education institutions. This Act caters for children with various disabilities inclusive of children with Deaf-blindness. The overall goal of educating learners with disabilities is to prepare them for adulthood with independent living. Education provides opportunities for acquisition of knowledge and skills that lead to personal independence and social responsibility (IDEA, 2004). Educating a Deaf-blind child involves several strategies that act as treatment options for the child. The overall goal of education therapy is to promote more typical social and communication behaviour which increase the child's ability to function and learn. The primary goals of education are to maximize the child's ultimate functional independence, quality of life by minimizing the core features of deaf-blindness and thus facilitating development and learning through socialization (Myers & Johnson, 2007).

Persons with deaf-blindness experience difficulties in daily life and require rehabilitation in a life perspective. They have difficulties in communication, social interactions and independent living. As such management of children with deaf-blindness is mainly concerned with mitigation of the challenges faced which result in isolation, difficulties in communication and independent living. Communication is particularly an important issue for deaf-blind people, due to the significance of both hearing and vision for communication by non-disabled people, leading to possible barriers, exclusion, and isolation. Many deaf-blind people need support with communication, access to information, and mobility (Bodsworth, Clare, Simblett, and Deafblind UK, 2011). It is however not known how special educators in Zambian special schools help learners with deaf-blindness attain communication skills and survival skills which are needed for increased participation and day to day living hence the need for the present study.

2.3 Parental Involvement and Social management

Management of children with deaf-blindness entails that parents and caregivers build relationships with each person living with deaf-blindness, and facilitate connections with family, peers, and others in their homes and communities. Without the opportunity to form meaningful relationships the person will not be able to distinguish other people from objects or tools in their environment (Van Dijk, J, 1999). Furthermore, persons who lose a second distance sense after they have lost the first sense face isolation and emotional pain as a result of the limitations imposed by the dual sensory loss, and experience great frustration due to the need to modify known ways of communicating and functioning. They are at risk of developing mental health conditions, such as depression.

A successful education program is one which consists of partnerships between parents and teachers of learners with special needs (Todd et al, 2014). Due to the core characteristics of deaf-blindness, there is need for both teacher and parental fostering of social modelling in the school and home environment for proper transition and acquisition of desired social, communication and daily living skills. Parents have a role to play in the education of the child as they are involved in the development and implementation of interventions. Parents are the first care takers and ones to discover the developmental delays in the child hence, are in better position to know the child's weaknesses and strengths, likes and dislikes which the teacher can later capitalize on. The parents play multiple roles in the child's life. They are first key informants in the diagnosis and treatment of the disability and later enrolling the child into school set up. The parents play important roles in the education of the child with deaf-blindness such as advocating in the education process, decision making and ongoing consultations, participation in the IEP, providing special education materials and taking part in the transition process. Parents and caregivers also can ensure that the skills learnt in school are transferred to the home environment in order to model the child's social and communication development. When stakeholders (families, service providers, persons living with deaf-blindness) and organizations collaborate, they build collective expertise that is much greater than that of any one person. However the level of parental involvement in the education of deaf-blind children in Zambia is not known.

CHAPTER THREE METHODOLOGY

3.0 Introduction

This chapter discusses the methodology which will be used in the study. It starts with a description of the research design that will be employed, the target population, sample size, the sampling procedures and research instruments to be used. Furthermore, it describes the data collection procedures and how data will be analysed to answer the research questions.

3.1 Research Design

This study took a Qualitative approach and use a Descriptive Research Design. The major purpose of descriptive research is description of the state of affairs as it exists and can be information about people's attitudes, opinions, habits, education or social issues (Kombo & Tromp, 2006). Kasonde (2013) describes a research design as merely a set of logical steps taken by a researcher to answer the research questions and is chosen by the researcher according to his or her assumptions or preference and experience in research. Descriptive research design was preferred in this study because it will help to investigate the particular case of deaf-blindness collectively from the schools with common features and understand and analyse in detail on the issues concerning learners with deaf-blindness.

3.2 Population of the Study

Oson and Onen (2009) refer to a target population as the total environment of interest to the one carrying out research. In other words, population is a group of individuals, objects or items from which samples are taken for measurement. It refers to an entire group of persons or elements that have at least one thing in common (Phiri, 2006).

The population consisted of primary class teachers who teach children with deaf-blindness, Parents and School Head teachers of learners with deaf-blindness in Lusaka district.

3.3 Sample Size

The sample size for the study constituted of two (2) Special Schools, twenty-six (26) respondents of which twelve (12) are teachers, twelve (12) are parents and two (2) head teachers of the selected schools. A sample size according to White (2003) is a subset or group of subjects from the lagers population and whose characteristics can be generalized to the entire population.

3.3.1 Characteristics of Respondents.

Table 1: Participants' gender

Participants	Female	Male	Total of participants	
Head teachers		1	1	2
Teachers	11	1		12
Parents	10	2		12

Table 2: Teachers' qualifications

Qualifications	Number of Teachers
Masters	2
Degree	3
Diploma	4
Certificate	3
Total	12

Table 3: Teachers' number of years in service

Number of years	Number of Teachers
0-10	5
11-20	4
21-30	3
31-40	0
41-50	0
Total	12

Table 4: Parents Residential characteristics

High Density Area	Low Density Area
7	5

3.4 Sampling Techniques

A sampling technique is a plan that explains how the respondents for the study are to be selected from the population (Kasonde, 2013). A sampling technique merely helps the researcher in selecting those to participate in the study. The study will use Purposive sampling procedure in the selection of two (2) special schools of learners with deaf-blindness, teachers who teach children with deaf-blindness, head teachers and parents of deaf-blind learners. Purposive sampling procedure was used to target and select purposively the schools that have learners with deaf-blindness, teachers and head teachers who have children with Deaf-blindness who could give rich first-hand information on the topic with real experience.

3.5 Research Instruments

Interview guides (Appendix 1, 2, 3) and an Observation Checklist (Appendix 4) were used to collect data. Interview guides both had open and closed ended questions which were used to obtain information from teachers, parents and head teachers of children with deaf-blindness. Interviews were used to gather in-depth and specific information from the respondents on the particular Case Study of management strategies of deaf-blindness in schools and because of the flexibility of open and closed questions which yield in-depth information.

An Observation checklist was used to gather information on the preparation and delivery of lessons and extra-curricular activities of the school. The checklist was also used to gather information of the actual behaviours of educators and learners and strategies that are used on children with deaf-blindness.

3.6 Data collection Procedure

Data collection refers to the gathering of information to serve or prove some facts. The researcher sought written permission which was presented to the participants. The researcher will get clearance from ethical committee, and got a letter of introduction from DBI secretariat. This was presented to the parents and schools visited to access participants. The open ended questions which required the respondent to answer yes/no provided information which required a wide range of responses. The closed-ended questions provided varying information from the respondents.

Interviews were used to collect data. The researcher used pen, paper, emails, video calls and a phone recorder to record data from interviews.

3.7 Data Analysis

Data analysis involves uncovering underlying structures, extracting important variables, detecting any anomalies and testing any underlying assumptions (Kombo & Tromp, 2006). Data analysis helps a researcher to thoroughly arrange and present the data collected. The data collected from the interview guides and observation checklist was analyzed by thematic analysis. Responses from respondents and observations were categorized and grouped creating themes and interpreted in line

with the research objectives. Here data will be classified in themes and sub-themes emerged and manipulated into tables and direct quotations from the information that respondents will give.

3.8 Ethical Considerations

Ethical issues in research are the dos and don'ts of any research undertaking. The measures undertaken to ensure compliance with ethical issues includes, keeping the identity of the respondents confidential. As rightly identified by Wimmer and Dominick (1994), the principle of confidentiality and respect are the most important ethical requiring compliance on the part of the research. The ethical requirements demand that the researcher respects the rights, values and decisions of the respondents. Thus, the respondents were assured that the information they were providing was for academic purpose only and their names as well as those of the school or institution will not be disclosed. The respondents reserved the rights to provide the information or withdraw from the research.

3.9 Trustworthiness of the Study

The term validity refers to the extent to which research truly measures that which it was intended to measure or how truthful the research results are and reliability as a measure of how consistent the results from a test are (Kombo & Tromp 2006).

A pilot study was carried out before the actual research on two schools to help with issues of reliability and validity of the study instruments. The researcher also used persistent observations during the research which helped to verify the study findings from the interviews and member checking to check accuracy of information obtained.

3.10 Summary

In this chapter, the methodology of the study was presented. It comprised of the study design, target population, sample size, sampling procedure, research instruments, data collection instrument used, data analysis, validation and reliability, pilot study and ethical considerations. The chapter also revealed that the study will employ a descriptive case study approach.

CHAPTER FOUR PRESENTATION OF FINDINGS

4.0 Overview

This chapter presents the findings of the study which are presented according to the research questions of the study and themes generated from the questions. The questions of the study were:

1. To determine the management strategies used in meeting the needs of learners with deaf-blindness in schools.
2. To establish parental involvement in the management strategies of learners with deaf-blindness
3. To establish challenges faced in the management strategies of learners with deaf-blindness.

The participants and schools were given identifiers to help differentiate the respondents as follows; Schools identified as special school A and B. Head teachers and teachers identified by gender and school represented above. Special tutor will be identified as ST1. Parents identified by gender, school their child attends and residential area such as high and low density areas.

4.1 Management Strategies Used in Meeting the Needs of Learners with Deaf-Blindness in Schools

Firstly, head teachers and teachers were asked whether or not if they had learners with deaf-blindness in their schools. The study found that both head teachers and teachers admitted to having learners with deaf-blindness in the two sampled special schools. A total number of 12 learners with deaf-blindness were found from the 2 schools at the time the research was carried out with most of the children having been diagnosed with the disability at the University Teaching Hospital while one child was born deaf and acquired blindness in her early years of adolescence and was being tutored from home.

4.1.1 Head Teacher's Views on Educational Management Strategies of Deaf-Blind Learners

Firstly, head teachers were asked to state measures used in schools to accommodate learners with deaf-blindness and measures such as restructuring learning environment, allocation of specialized materials and sensitization of peers were given.

4.1.2 Modification of Learning Environment and Sensitization

The head teachers reported that modification of the learning environment and allocation of specialized materials are important measures in accommodating learners with deaf-blindness in schools. In addition the head teachers reported that allocation of qualified teachers, structured learning process and sensitization in the schools were measures taken in accommodation of deaf-blind learners.

A female head teacher from a special school A said,

We restructure the learning environment to readdress the deficits in communication, imagination and socialisation domains of the learner with deaf-blindness. You know the only way to accommodate that learner is to look at their different challenges in dai-

ly living so you understand their individual strengths since the severity and level of deaf-blindness differ from one child to another.

A male head teachers from special unit school B emphasized that,

Children with deaf-blindness get different treatment from their peers from the regular classes so we start by sensitizing the other learners to appreciate and accommodate their fellow learners with deaf-blindness though with challenges involved as you know perceptions vary.

4.1.3 Allocation of Specialized Materials

In order to have an in-depth understanding on educational management of learners with deaf-blindness, head teachers were asked if learners with deaf-blindness require specialized materials in school. The information collected from all schools visited indicate that all head teachers agreed that learners with deaf-blindness require specialized materials in learning.

Female head teacher from special school A had this to say,

You know children with deaf-blindless lack communication and socialization with environment therefore they need materials that can make them learn to socialize with their environment and also communicate. You know they need practical hands on objects or tactile materials which can help them develop communication and social skills.

Another male head teacher from special school B indicated the following,

Dealing with a child with deaf-blindness cannot be without materials those children naturally communicate through touching and feeling objects.

In summary, the head teachers gave similar and different views on educational management strategies such as restructuring the learning environments to suit needs of learners, allocating tactile materials to the learners to improve communication skills, and also sensitizing peers to appreciate peers with deaf-blindness.

4.1.4 Teacher's Views on Educational Management Strategies of Learners with Deaf-blindness.

Being key players in the management of learners with deaf-blindness, teachers were firstly asked what they understood by the term deaf-blindness and numerous responses were given among which most referred to deaf-blindness as a condition where one has lost both the sense of hearing and the sense of sight.

4.1.4.1 Teaching Goals

In understanding better on the management of learners with deaf-blindness, teachers were asked the teaching goals of the children with deaf-blindness. Commonly, teachers lamented that the regular curriculum offered in schools was not relevant

in meeting the needs of their learners. The teachers reported that as a result of this the goals depended on each child's level of disability. One male teacher from special school B reported that,

Goals depend on whether the condition is severe mild or moderate. Those with mild to moderate (appear to have either residue hearing or vision) our goal is to mainstream them to upper grades in the regular classes after acquiring communication skills and basics then those severe we want them to attain ADL and independence.

A female teacher from a special school A pointed out that,

The goal is to help those with mild deaf-blindness to progress to higher grades while those with severe to attain independence for daily living like toileting, cooking, feeding, sensory input, dressing, personal hygiene and to be able to communicate their needs.

A male teacher, ST who was assigned to teach a girl child who acquired deaf-blindness in her early stage of adolescence discussed his approach,

Since the blindness is acquired, my goal right now is to help her learn braille so that she can continue with her education in schools for the visually impaired. She knows sign language so I use tactile signs to teach her the different braille symbols. And so far we are making progress.

It was evident from the observations that those with severe deaf-blindness were taught activities daily living skills to promote communication and independent living and the teaching goals for those with mild or moderate deaf-blindness were to help them transition into mainstream classrooms.

4.1.4.2 Instructional Strategies

Teachers were then asked on the instructional strategies used to meet the needs of their learners with deaf-blindness. Teacher's responses varied but the majority reported to having difficulties on the teaching strategies to use but however use strategies according to the individual child. A female teacher from special school A mentioned one to one learning because of the uniqueness of each child and also lamented that,

What I feel is that we graduate from college without really understanding how to teach these children. You find strategies on your own when you even did not learn about it. There is a lot to be done. Sometimes you never know what approach to take to make sure the child understands what you are trying to communicate.

Another female teacher from unit B reported,

Since it impairs both the sense of hearing and sense of sight we strive to use tactile approach to engage them in activities that are learner centered and mostly on one to one basis with toys and real objects. IEP are ideal because they help us plan activities which parents can help with when at home.

Other teachers emphasized the need to create a spacious environment with less furniture to ease mobility and to also allow the child to gain confidence. They said,

Overcrowding of classrooms tend to make the child confused when there are so many objects around. If you want the child who is deaf-blind to learn what is in their environment and how to navigate, limit objects until they are familiar with surrounding after which you can introduce new objects.

The researcher noted through observations of lessons that learning was planned on individual basis. Individualized Education Plans (IEPs) were drafted for each individual child. However all teachers employed the same methods of teaching.

As teaching and learning does not go by without using a curriculum, teachers were then asked if the national curriculum is relevant in meeting the needs of learners with deaf-blindness. The findings of the study revealed that ten (10) teachers which is the majority said the curriculum is not relevant in meeting the needs of learners with deaf-blindness whilst two (2) teachers said the curriculum is relevant for those who had residual hearing and sight.

One teacher from a special unit B said:

It is not relevant for our learners because there are no resources for teaching deaf-blind learners. Our main focus is to teach them ADL skills. So we make our own curriculum which we follow.

Another teacher from a special unit B pointed out that,

It is not relevant to the needs of deaf-blind learners in terms of achieving social interactions and mobility. It is too academic so we modify it to suit our learners. We want to teach them something beyond that.

On the other hand, of the 2 teachers who said the curriculum is relevant, one female teacher from a special school A stated that,

Other topics are relevant for our learners because they have some residual hearing and sight and we are trying to integrate them into mainstream schools so modify the content to teach them at their own pace but we don't adopt our own.

4.1.4.3 Specialized Teaching and Learning Materials

Teachers were further asked on the specialized teaching materials and aids used for learners with deaf-blindness. The majority of the teachers emphasized the use of real and tactile objects. The common teaching materials mentioned included bright materials, toys, building blocks, charts, balls and ADL materials. Many teachers were of the view of using toys as this helps the child understand what is in their environment better.

One female teacher from a special school A noted that,

We engage materials and activities that promote social interactions and communication but we have challenges accessing practical objects.

Another female teacher from the same special school A lamented that,

Learners with deaf-blindness need to use materials that are both at home and school to continue the routine process of learning.

A male teacher from special school B added that,

We use materials that promote communication. For example, we use the technique of tapping on drums or tables to communicate a need.

It was evident through observations that teachers strived to use materials that would promote communication and independence in children with deaf-blindness despite lack of availability of teaching and learning materials in the schools.

One female teacher from a special school B explained that,

Do we even have specialized materials, you know we just modify local materials whatever is in our means we use to teach because we won't teach if we wait for specialized materials.

Another female teacher from a special unit B observed that,

Sourcing materials for our learners with deaf-blindness is a challenge but we try to source required materials from their parents but you find that most come from poverty stricken homes. So we get what is close to what is found in their home environment and use to teach them.

Lastly when teachers were asked if learners were engaged in extra-curricular activities, some teachers said they included learners in sporting activities, P.E, culture (dancing, cooking, sweeping), whilst other teachers indicated that it is difficult to engage children with deaf-blindness in extra-curricular activities due to their lack of social interaction. A female teacher at special unit B pointed out that,

There are no extra-curricular activities to engage learners with deaf-blindness to because of the lack of resources.

4.2 Parental Involvement in Management Strategies of Learners with Deaf-blindness in Schools

In trying to investigate parental involvement in the education of learners with deaf-blindness, the researcher interviewed head teachers, teachers and parents. The findings will be presented according to views from the head teachers, teachers and the parents.

4.2.1 Head Teacher's Views on Parental Involvement in Management Strategies for Learners with Deaf-blindness in School

Firstly, head teachers were asked if parents are involved in the education of their children and the findings of the study revealed that all head teachers said both yes and no to parents being involved. For example, the female head teacher from special school A explained that,

I say yes and no because not all parents are engaged in the learning of their children apart from delivering the necessities. For some it is like a relief to drop the child at school what happens there they don't mind. In certain instances, we have heard that parents are still hiding their children in the homes.

Another male head teacher from special school B said,

Yes some parents are involved in the education because they respond when invite them for programs apart from bringing their children to school.

The head teachers were then asked on how the school provided opportunities for parents to be involved. Various responses came forth of which through school programmes, parent meetings, open day and PTA were common. Other findings revealed that interactions with parents when they bring their children and workshops with parents were other measures given.

The female head teacher from special school A pointed out that,

We teach parents strategies that they can use on the child because you know when managing a child with deaf-blindness should be the same at home and at school. They need routines not to get confused so we sit down with parents to develop a program.

A male head teacher from special school B added to say,

You know the learning of a child with a disability and that of one without is different. The parent to a disabled child is the first educator so we strive to involve them so we can share ideas through meetings or open day meetings to help with how we can handle the children.

The head teachers interviewed revealed that, upon enrollment into school, parents of children with deaf-blindness are encouraged to plan for the management strategies of their child in the school with the school management.

4.2.2 Teachers Views on Parental Involvement in Management Strategies for Learners with Deaf-blindness in School

When teachers were asked if parents of children with deaf-blindness are involved in the education of their children, the findings of the study revealed that other parents were involved whilst others were not involved in the management of their children with deaf-blindness. Teachers were also asked how they provided opportunities for parental involvement and the majority of teachers said parents are involved through

IEP, home based rehabilitation, open day, meetings and discussions. One female teacher at a special school B said,

We call for meetings with the parents especially when trying to plan for the learners for routines to continue at home. We have parental orientation with new parents to help them carry on with their children.

Another female teacher from the same special school B noted that,

Most children with deaf-blindness especially those with late intervention have poor toileting skills so you know we have to work with their parents so that they learn how we manage their children in the school and how their children communicate their need to answer the call of nature.

A female teacher from special unit A class teacher indicated that,

Due to the fact that our teaching strategies are all through IEPs parental involvement is inevitable as we need parents input to create an IEP for their child,

On the other hand, teachers also mentioned that other parents are not involved in the management of learners with Deaf-blindness. One female teacher from a special school A pointed out that,

Others are not involved because they have to work and most of these children come from poverty stricken homes which are very far from here and you find that they fail teaching the child from home because they have no time. They are busy looking for food for their family.

Another teacher from special unit B said,

Some parents do not find it worthwhile to invest in children with disabilities you find that they would rather not attend PTA for their other children. They even send siblings sometimes to represent them now surely what can you discuss with them?

4.2.3 Parental Involvement in Management strategies for Learners with Deaf-blindness in Schools

In order to have a clear understanding on parental involvement the researcher interviewed parents of children with deaf-blindness. 7 Parents resided in High density populated residential areas while 5 from Low density areas. Parents were first asked on where their children were diagnosed with deaf-blindness and the study revealed that the children were diagnosed at the University Teaching Hospital.

Parents were then asked on how they have been coping to the disability and different views were brought out. One parent from a high density area, special school A mentioned that,

I have tried my best on my child. Most ways are through what the teachers tell us like toileting but I don't manage to teach my child at home.

Another parent from a low density area, special school A said,

I have learnt some copying strategies from the University Teaching Hospital where we go every Thursday, like not beating my child when she messes herself but clean her up the continue with helping her on how to communicate her need to use the toilet. It has been very difficult but we are trying.

Another parent from a low density, whose child was being tutored from home had this to say,

It has been difficult with my child because she was born deaf and later became blind. After her diagnosis I was not told anything on how to handle a deaf-blind child and up to now I just know what the teachers just say and it's the only thing that has helped so far but I don't know what to do really. But now the teachers are teaching her braille I am hoping this will improve communication with her and also help her finish school.

The study further sought to establish the extent to which parents are involved in the education of their children with deaf-blindness and how schools provided opportunities for their involvement. Different views were given. Half of the parents revealed that they were involved in school activities for their children whilst the other population said they were not.

One female parent from low density area, special school A pointed out that,

I attend PTA meetings and discussion when am called at the school and I help with tasks we are required to do at home which the teachers give. I am also able to buy materials which are needed for my child.

Another female parent from high density area special school A with a different view said,

I do not understand deaf-blindness and am the only parent doing a small business to fend for my family and it's not easy to buy what the child requires. My husband is a drunk and does not support us he says it's a waste of time and resources taking him to. It's hard.

A female parent from low density area, special school B lamented that,

The school does not provide opportunities for me to be involved in my child's education. I have personally taken interest because she is my inspiration. I use my own little resources to make her life easy and happy. I am always willing to learn about deaf-blindness and this is why I have taken up pursuing a master's degree in the same field so that I can understand more on how to manage my child and also better the lives of deaf-blind children in Zambia.

4.3 Challenges Faced in the Management Strategies of Learners with Deaf-blindness

On the challenges that head teachers, teachers and parents face in the managing strategies of children with deaf-blindness, data was collected through use of in-

interviews and observations of school and classroom activities. The findings are the presented starting with the head teachers, teachers then parent's challenges.

4.3.1 Head Teachers' Views

Several views were echoed by the head teachers when asked on the challenges faced in the management of learners with deaf-blindness. Most of the head teachers responded that the lack of materials, poor pre-service training, funding, communication barriers of learners, lack of professionals and parental understanding on deaf-blindness are the major challenges faced when handling deaf-blind learners in school.

4.3.3.1 Lack of Knowledge and Specialized Professionals

Commonly, almost all of the head teachers mentioned that even though they have qualified personnel, they are not specifically trained to handle children with deaf-blindness. The female head teacher from special school A lamented that,

We are not trained on the appropriate practical strategies to reach out to learners with deaf-blindness. Our educational institutions focus on management of either deaf or blind children but not a combination of both. We also don't have collaboration with other line ministries that can help reach deaf-blind children like the Ministry of health to form strategies together on a round table you know.

Another male head at special unit B said,

We have challenges when coming up with a multi-disciplinary team because of lack of financial resources to support involvement of professionals, hence a lot of work is left and lamped in the hands of a teacher who is supposed to be a psychologist, caregiver, occupational therapist etc because these people are not there.

A female head teacher at special school A had this to say,

You know I had the privilege to attend a workshop at the University of Minnesota and comparing what we get from our local colleges and university I tell you here in Zambia we are doing nothing in terms of reaching out to children with deaf-blindness.

4.3.3.2 Adequate Personnel

As the head teachers complained of the lack of trained personnel on deaf-blindness, they also mentioned the lack of adequate personnel to meet the needs of the learners, the male head teacher from special school B explained that,

Deaf-blind learners need one to one attention. Here in Zambia we are not given that number of staff therefore time management is quite a challenge. One teacher may need to attend to different learners

The researcher through observations also noted that teachers were under staffed comparing the numbers of pupils with other disabilities who were also in need of their attention in the schools in the schools.

4.3.3.3 Lack of Teaching and Learning Materials and Parental Involvement

The head teachers complained on the lack of materials and equipment to help deaf-blind learners. This was also observed by the researcher.

Deaf-blind children require specialized materials at schools. A male head teacher from special unit B lamented

We do not have assistive devices that can help in teaching deaf-blind children such as braille pads, braille computers and braille books because of lack of funding.

The involvement of parents was another challenge emphasized. A female head teacher from special unit A mentioned that,

It is a challenge to us because most parents don't understand the deaf-blindness they think it is a condition that cannot be helped and end up enrolling the child late when they have already passed elementary stages where positive behaviours are easy to mold.

4.3.2 Teachers' Views

Being the educators of learners with deaf-blindness, teachers were asked on the challenges faced when managing children with deaf-blindness. The majority responded that lack of knowledge, resources, transportation, communication barriers, relevant curriculum, collaboration on IEP, absenteeism, teacher motivation and discrimination from regular classes are the major challenges in managing children with deaf-blindness.

4.3.2.1 Lack of Knowledge on Disability

Surprisingly, even though most teachers in the special schools and units were trained in special education, the majority complained to have no proper knowledge on the disability. One female teacher from special school A pointed out that,

What I feel is that we graduate from college without really understanding how to reach out to these children. You find strategies on your own when you even didn't learn about it. There is a lot to be done.

A male teacher at special school B revealed that,

The knowledge I have on deaf-blindness through my training is not practical enough to meet the specific needs of learners. Look at Unza and Zamise they do not offer specific full year courses on deaf-blindness but a course on visual/hearing impairment is there maybe if we were trained on deaf-blindness on its own we would have had wider knowledge.

4.3.2.2 Lack of Resources, Specialize Professionals and Relevant Curriculum

Many teachers mentioned the lack of resources, specialized therapists and relevance of the curriculum as the main challenges faced in management of children with deaf-blindness. It was pointed out that dealing with children with deaf-blindness involves activities for daily living and social interaction which require materials. One female teacher at special unit B mentioned that,

The topics in the curriculum are not relevant to children with deaf-blindness looking at their daily routines and rituals.

Another female teacher from special school A said,

Children with deaf-blindness need to use various activities when learning. All learning involves use of tactile objects but we do not have everything hence it is difficult to teach. Real objects are the only materials that help the deaf-blind child understand what is in their environment. And you know our catchment area most of the learners come from families which are not well to do so they can't help us with all required materials.

Through observations of the lessons the researcher noted that the schools lacked specialized teaching materials, visual aids, toys. Teachers explained that they try to find local materials and modify but it is difficult as there is less funding towards special education.

Teachers added on that there are no motivational allowances in schools. One female teacher at special unit B explained that,

Grants are low it is merely a drop in the ocean. Administration would rather stock in the normal classes and laboratories and look at abilities of special children to be going nowhere.

4.3.2.4 Absenteeism of Learners and Lack of Parental Involvement

The findings of the study from the teachers revealed that most of the learners with deaf-blindness came from high density areas and that the lack of proper transportation caused absenteeism. One female teacher explained that,

It draws us back in the learning because routines are disturbed and you find that you start from scratch the day the learner decides to class and parents also don't help with reinforcing the tasks we give at home.

4.3.3 Parents' Views

Parents were also interviewed on the challenges faced in management of their children with deaf-blindness in school. The common challenges that were mentioned included communication barriers, lack of knowledge on the disability, finances, and transportation of child to school, negative attitudes and the lack of time.

4.3.3.1 Lack of knowledge on the disability, Schools involving parents in school activities & Discrimination.

The majority of the parents pointed out the lack of knowledge on the disability. One female parent from high-density area, special school A explained that,

After diagnosis at the University teaching hospital I was not told what to do next until I enrolled my child in school after asking around in the compound. I would like to learn more about it maybe I can help my child.

Another female parent from high-density area, special school A mentioned,

You know I am not well educated and understanding this same thing my child has is difficult. The doctor just said your child is both deaf and blind. I would love to find other people that have children like this maybe I can learn more from them.

A female parent from low density area, whose child was being tutored from home pointed out that,

We had to settle for home schooling after my daughter became deaf. She had been in a deaf unit prior becoming deaf-blind. We realized that she was encountering a lot of discrimination and was no longer interacting with her peers. The teachers at the school were only specialized in teaching the deaf so she was mostly neglected in class and did not learn anything at all.

Another female parent from low density area whose child was at special school B lamented,

The challenges have been so many, communication has been the most challenging because sometimes I don't get what she needs. Access to the environment is also hard because the area where we live has many stones and sometimes she wants to walk outside barefoot and ends up hurting herself, so mobility is hard. I also have a challenge with transporting her to school. You know special schools which handle deaf-blind children are few and we live very far from the school so transport is very difficult.

Additionally, some parents mentioned on the negative attitudes from the community and lack of association and interaction with other parents in the same situation. It was revealed that many parents wanted to be part of support groups that can help them share ideas on how to manage their deaf-blind children.

4.3.3.2 Finances and Time to be involved in School Activities

It was also noted that the majority of parents came from high density areas and they complained on lack of finances to support their children. One parent from special school A said that,

I do not work and my husband does piece work and the little he makes cannot allow us to buy school requirements. Sometimes my child remains for school because of no transport.

Other parents complained on not having time to attend to their children and of the negative attitudes from society. One female parent from low density area, special unit B explained that,

I used to work and was on studies but I stopped in order to help control my child at home but now that he has learnt a few things I started business.

A male parent from low density area, special school A lamented that,

My work schedule is very involving hence I miss school meetings and I use his siblings to represent me or take the child to school but I buy the materials needed.

It was observed that the majority of parents send siblings or care takers to take and collect their children on their behalf from school.

4.4 Summary

The above chapter presented findings of the study according to the themes; management of learners with deaf-blindness in school, parental involvement in the management of learners with deaf-blindness and challenges faced in management of learners. The findings of the study revealed that management of children with deaf-blindness is based on the individual child due to the characteristics of the disability. Head teachers accommodate learners with deaf-blindness in school by modifying the learning environment, allocating specialized materials and structured learning. The goals of educating children with deaf-blindness depend on the severity of the disability. Emphasis has been placed on teaching children activities for daily living and independence. Management strategies put in place involved the use of visual tactile charts, real objects, toys and instructional strategies that foster social interaction and communication. Coming to parental involvement in the learning of children with deaf-blindness, some parents are involved whilst others are not and parental involvement is mainly on called for meetings, PTA and sports and cultural activities. Lastly, the challenges faced by head teachers, teachers and parents included the lack of knowledge on the disability, poor-pre service training, lack of specialized materials and collaboration on IEP, communication barriers with deaf-blind learners, relevant curriculum, absenteeism of learners and discrimination of learners with deaf-blindness. The next chapter is chapter five which discusses the findings of the study.

CHAPTER FIVE DISCUSSION OF FINDINGS

5.0 Introduction

This chapter presents the discussion of findings which are aimed at investigating the management of learners with deaf-blindness in selected primary schools of Lusaka district. The findings are presented according to themes that were derived from the study objectives which include: To determine the management strategies

used in meeting the needs of learners with deaf-blindness in schools; To establish parental involvement in the management strategies of learners with deaf-blindness; To establish challenges faced in the management strategies of learners with deaf-blindness. The discussion of findings from head teachers, teachers and parents are integrated.

5.1 Management Strategies of Learners with Deaf-blindness

The combination of loss of functional use of vision and hearing greatly impairs an individual's ability to gather visual and auditory information. Educating a Deaf-blind child involves several strategies that act as treatment options for the child. The overall goal of education therapy is to promote more typical social and communication behaviour which increase the child's ability to function and learn. The primary goals of education are to maximize the child's ultimate functional independence, quality of life by minimizing the core features of deaf-blindness and thus facilitating development and learning through socialization (Myers & Johnson, 2007).

In this regard the study revealed different strategies employed by educators which highly depended on their understanding of deaf-blindness. The common responses that came out from teachers on the understanding of deaf-blindness were that children with deaf-blindness were those who could neither hear nor see. It was also discovered that although teachers were aware of the characteristics of deaf-blindness they were not fully trained to manage children with the disability and therefore management strategies were designed in relation to characteristics of deaf-blindness and were aimed at promoting communication, social interactions, independence and mobility. This revelation is in coloration with a study conducted by Bodsworth, Clare, Simblett, and Deafblind UK (2011) which revealed that communication is particularly an important issue for deaf-blind people because lack of communication leads to exclusion and isolation.

The findings of the study also revealed that head teachers accommodate learners in the schools with consideration of the disability. The majority of the head teachers reported modifying the learning environment and allocating specialized materials to learners with deaf-blindness in order to accommodate them in schools. Other head teachers reported the allocation of qualified teachers and structured learning processes as measures. Accommodating learners with deaf-blindness in inclusive special or regular schools cannot be done without the modification of the school and classroom environment. The researcher observed that indeed the learning environment was modified to accommodate deaf-blind learners and tactile/ real objects were used to teach the learners social and communication skills.

On educational management, the findings of the study revealed from all the teachers that the teaching goals depend on each child's level of disability. One teacher explained that, *"Goals depends on whether the deaf-blindness is severe, mild or moderate. Those mild to moderate our goal is to mainstream them to upper grades in the regular classes after they acquire daily living skills and then those severe we want them to attain ADL and independence."* The findings are in line with educational goals outlined by IDEA (2004) which state that the overall goal of educating learners with disabilities

is to prepare them for adulthood with independent living. Education provides opportunities for acquisition of knowledge and skills that lead to personal independence and social responsibility.

The majority of teachers from the schools reported to using instructional strategies that are on an individual basis. The teachers mentioned the use of an individualized education plan (IEP) as ideal in education of deaf-blind children because each child was unique and had perceived environment differently. This is in line with the Theory of Mind explained by Frith & Frith (2005) which suggests that children have different socio-cognitive functioning and therefore have their own level of understanding their environment. Using an Individualized Education Plan (IEP) is therefore important as it considers the unique needs and abilities of a child which includes ability to process information and communicate. An Individualized Education Plan is also important because it is a collaboration strategy that involves the teacher, parent or caregiver and a professional.

It is worth noting however that the instructional strategies employed did not involve any assistive devices or modern technology. All instructional materials involved were those which were improvised by teachers and were accessible within the school and community. Additionally, it can also be concluded then that teachers are not aware of the instructional strategies used on learners with deaf-blindness. Deaf-blindness is a low incident disability which requires unique instructional strategies which teachers need to consider. Majority of the teachers attributed the lack of knowledge to poor pre-service training and having minimal practical skills on instructional strategies to use to meet the needs of learners which means that the needs of the learners are not being fully met. One male teacher lamented that, *“what I feel is that we graduate college without understanding how to reach to these children.”* It was evident from the study findings that teachers are not adequately prepared to teach deaf-blind learners. There is need, therefore, to make deaf-blind pre-service training intense or be taught as a full course to allow adequate practical knowledge be obtained.

5.2 Parental Involvement in Management of Children with Deaf-Blindness

With regard to parental involvement in the management strategies of learners with deaf-blindness, it was established that the majority of parents are not involved in the school activities. The findings were consistent from the head teachers, teachers and the parents themselves. One head teacher mentioned that, *“I say yes and no because not all parents are engaged in the learning of their children apart from delivering the necessities. For some it is like a relief to drop the child at school what happens there they don't mind. In certain instances, we have heard that parents are still hiding their children in the homes.”* In line with the above findings, Desforges (2003) writes that schools that undertake and support strong comprehensive parental involvement efforts are more likely to produce learners who perform better than identical schools that do not involve parents. Likewise, Cooper & Nye, B (2002) survey of 709 parental involvements in special education found that as parents support for autonomy increased, the achievement of the children also increased.

From the findings, parental involvement in the education of the child with deaf-blindness is fundamental due to the nature of the disability which calls for a multi-disciplinary approach as routines, rules and signs given to the child at school need to be consistent in both the home and school environment. Unal & Unal (2014) allude that when parents and schools collaborate to make the child's program at home and school, the child benefits from the resulting consistency. In addition, various research findings by Henderson & Nancy, (1994), Williams et al, (2002) and Desforges, (2003) illustrated that effective schooling is with parental involvement and parents' potential contributions to schools.

It was also noted from the findings that most parents do not understand the nature of deaf-blindness but were willing to learn and be involved. However, the parents are rarely provided with the opportunity to get involved in their children's education. Some teachers admitted to not having enough activities to involve parents in apart from the IEP which most parents do not even take part in. Evident from the findings of the study, most parents of the children with deaf-blindness come from densely populated areas whilst a few from low density areas. One parent lamented that, *"I do not understand deaf-blindness and am the only parent doing a small business to fend for my family and it's not easy to buy what the child requires. My husband is a drunk and does not support us and am wasting time taking him to school. It's hard."* The findings are similar to the findings of Noor-Aziz (2015) study on parental involvement in special education in Pakistan provides that poor family structure affects parental involvement, relationship between economic factors and parental involvement and evidence that parental involvement highly impacts children achievements. Since children with deaf-blindness usually have communication and social problems, intervention needs to be across home and school settings. The family at home play a role in fostering development in those deficits.

Furthermore, the head teachers and teachers reported that they involve parents through activities such as IEPs, PTA, open day, meetings and discussions but however, emphasized that a majority of parents do not take part in the IEPs. It was also discovered from the parents that they do not take part in school activities because of the lack of knowledge on the disability whilst others attributed to having demanding jobs, businesses and others indicating that the schools did not provide them opportunities to be involved. There is need for collaboration between the parents of children with deaf-blindness and the schools to establish comprehensive strategies to use to educate deaf-blind learners.

5.3 Challenges Faced in the Management of Learners with Deaf-Blindness

A number of challenges were indicated by head teachers, teachers and parents that are faced when managing children with deaf-blindness. The challenges are school related and common of all given by the three groups of respondents is the challenge of the lack of knowledge on the disability and communication. One teacher lamented that, *"What I feel is that we graduate from college without really understanding how to reach out to these children. You find strategies on your own when you even didn't learn about it. There is a lot to be done"*. In Zambia, it is evident that although teachers graduate from special education institutions, no specific course places full focus on

deaf-blindness as a single area of study. Teachers graduate colleges and universities with knowledge of how to manage either deaf or blind learners but not a combination of the two disabilities.

The findings above suggest that the teachers are not fully qualified to teach learners with deaf-blindness if they do not understand the disability or have practical strategies to meet the needs of the learners. It can also be assumed that children with deaf-blindness are mismanaged and do not acquire a meaningful education that is supposed to help in minimizing the deficits of the disability that are characterized by social and communication problems, as the teachers reported to having low knowledge on the disability. The gap in available knowledge among professionals and common citizens has led to misunderstanding of the needs of children with deaf-blindness.

If the teachers indicate to acquiring training that does not help in understanding deaf-blindness as a disability, there is need therefore for local and international training workshops on practical strategies on managing children with deaf-blindness in schools and a review of the courses offered in colleges and universities of Zambia. One head teacher mentioned that, *"You know I had the privilege to attend a workshop at the University of Minnesota and comparing what we get from our local colleges and university I tell you here in Zambia we are doing nothing in terms of reaching out to children with deaf-blindness."* It is therefore important that teachers have an understanding of children with deaf-blindness. The Theory of Mind clearly explains that the typical characteristics of the impairment are needed to be understood by educators when coming up with strategies to meet the needs of deaf-blind learners given that the disability distorts the reception of information from the environment.

Communication is cardinal for education to take place. Difficulties in communication is one of the core characteristics of deaf-blindness. As earlier stipulated in preceding chapters deaf-blindness impairs ones' ability to functional use of hearing and sight. Without being able to neither see nor hear, it is difficult for one to gather information from their environment. The study revealed that educators and parents face challenges with communicating with deaf-blind children and however improvised hand on hand sign language to minimize the gap.

5.4 Summary

The chapter has discussed the findings of the study. The study revealed that management of children with deaf-blindness in primary schools is dependent on the teachers understanding of the characteristics of the disability and head teachers accommodate the learners by modifying the learning environment and allocating special teachers and materials. The goal of teaching learners with deaf-blindness depends on the child's abilities and level of disability which can be mild to progress to higher grades or severe to attain ADLs and the instructional strategies employed are highly individualized which were not however brought out by the teachers attributed to lack of understanding of the disability and poor pre-service training.

With regard to parental involvement, it was revealed that majority of parents are not involved whilst others are. Teachers attributed to having no activities to involve parents apart from IEP which most parents do not even take part in. It was established that there is poor teacher-parent collaboration.

On the challenges faced in management of learners with deaf-blindness in schools, commonly given from majority of respondents is the lack of knowledge on the disability and communication. Other challenges included the lack of funding, resources and materials, transport for learners, curriculum irrelevance and discrimination of learners with deaf-blindness from peers. The next chapter presents the conclusion and recommendations of the study.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.0 Introduction

This chapter presents the conclusion and recommendations drawn from the findings of the study. The study was to investigate the management of learners with deaf-blindness in selected primary schools of Lusaka district. The study further aimed at establishing parental involvement in the management of learners with deaf-blindness and later identified the challenges faced in the management of learners with the disability.

6.1 Conclusion

The study established that management of children with deaf-blindness in primary special schools and units is dependent on the teachers understanding of the characteristics of the disability and is highly individualized. Head teachers and teachers from the visited schools gave out various educational and social management strategies that are used to meet the needs of learners. Even though strategies were given, it was acknowledged from the head teachers and teachers that there are not fully trained to meet the needs of learners with deaf-blindness and attributed to poor-pre service training and low knowledge levels on deaf-blindness. The study established that those children with mild to moderate deaf-blindness progress to higher learning whilst the severe are mainly taught Activities for Daily Living (ADL). Instructional strategies are individual based and all teachers mentioned the use of an Individualized Education Plan (IEP).

As deaf-blindness is characterized by deficits in social communication, the study established that teachers use tactile sign language (hand on hand), real objects and tactile charts that foster social interactions and thereby ease communication.

With regards to parental involvement, the study established that the majority of parents are not involved in the management of learners with deaf-blindness in schools whilst others are. Most of the parents who are not involved gave out different reasons such as the lack of understanding on the disability, busy with work or busi-

nesses whilst others mentioned that schools do not give them opportunities to be involved. It was also revealed from the teachers that they have no other activities to involve parents apart from the IEP which most parents do not even take part in. It is concluded that there is poor teacher-parent collaboration caused by both parties.

The study further identified the challenges faced in management of learners with deaf-blindness in schools from all the respondents which were head teachers, teachers and parents. It was established that there are low knowledge levels on deaf-blindness understanding. Teachers attributed to poor pre-service training which did not yield practical skills on managing children with deaf-blindness. Parents also lack understanding of the disability and most revealed that they came to learn of the condition after diagnosis from the doctors who do not explain further on how to manage the disability. It can be concluded then that there is lack of proper teacher preparation programs in colleges and universities that can adequately train teachers to effectively meet the needs of children with deaf-blindness in schools.

Other challenges included the lack of funding, resources, materials and transportation for learners. It was revealed that there is low funding towards special education which makes it hard to buy materials needed for the children. The teachers also mentioned that the curriculum is not relevant in meeting the social and communication characteristics of learners with deaf-blindness. And thus, it can be concluded then that the needs of learners with deaf-blindness are not fully met. Lastly, there is discrimination of learners from their peers and in the communities. Negative attitudes hinder social interactions of learners with deaf-blindness with peers and simultaneously hinder development of communication skills.

All in all, the study established that teachers are not adequately trained to meet the needs of learners with deaf-blindness in the schools. The management strategies for this disability are supposed to act as treatment options for the child from the school to home environment. There is need for intense pre-service training to help students attain practical knowledge on the disability to help come up with strategies that will help improve the lives of the learners. Children with deaf-blindness require specialized materials which are not readily available in the schools to help foster independence and social interactions. There is need for funding for the specialized materials required for the learners. As the learning of children with special needs is with the involvement of the parent, there is need for the schools to come up with strategies collectively with parents in order to help the child to learn as routines and rituals are the same for learners with deaf-blindness at home and school. Awareness from diagnosis can help to educate parents on the disability as the study established low knowledge levels on the disability from the parents which can in turn help them to contribute in the management of the condition.

6.2 Recommendations

Based on the study findings, the following recommendations are made:

1. Workshops and seminars for in-service teachers to be held on teaching learners with deaf-blindness to increase knowledge levels.

2. Teacher training programs in colleges and universities to be revised to meet the current needs of learners with deaf-blindness.
3. Distribution of the required specialized materials and assistive devices in schools to foster teaching and learning of children with deaf-blindness.
4. The Ministry of General Education to liaison with the Ministry of Health in providing education to parents through support groups upon diagnosis.
5. Sensitizing schools, regular teachers and administrators against discrimination of learners with deaf-blindness
6. The Ministry of General Education to revise the 2013 Curriculum on special education to suit the goals and needs of learners with various disabilities.

6.3 Recommendation for future research

1. The role and importance of parental involvement in the education of deaf-blind children
2. Intervention strategies for children with deaf-blindness
3. Challenges teachers face when teaching braille to deaf-blind children

References

- Alsop, L. (Ed.). (2002). *Understanding Deafblindness: Issues, perspectives, and strategies*. Logan, UT: SKIHI Institute.
- Astington, J & Jenkins, J (2008). Theory of Mind Development and social Understanding. *Journal cognition and emotion* Vol9, 1995-issue-2(3) (2010).
- Astington, J& Edward M.J. (2010) .The Development of Theory of Mind in Early Childhood. *Encyclopaedia of infant and early childhood dev.*
- Astington, J & Dack, L.A, (2008) Theory of Mind. In: Haith MMJB, eds. *Encyclopaedia of infant and early childhood dev.* Vol 3. San Diego, CAC: Academic Prev: 343-356.
- Brown, D. (2008). 'The sensory integration perspective and what it offers us in the field of deafblindness', Parts 1 & 2. *Dbl Review*, 42, 22-26.
- CBM (2015). Disability Inclusive Development Toolkit.
- Frith, E & Frith, U (2005) *Theory of Mind*. *Current biology* Vol 15 No 17 R644.
- Janssen, M. (Ed.); Souriau, J. (Ed.); Rodbroe, I. (Ed.). (2007-2009) *Communication and Congenital Deafblindness: Booklets II, III and IV*, Danish Resource Centre on Congenital Deafblindness (VCDBF), Denmark and Viataal, The Netherlands.
- Kombo, D.A., & Tromp, D.K (2006). *Proposal and thesis writing: an introduction*. Nairobi

McInnes, J. M., & Treffry, J. A. (1993). *Deaf-blind infants and children: A developmental guide*. University of Toronto Press.

Munsaka, E. & Matafwali, B. (2013). *Human Development from Conception to Adolescence: Typical and Atypical Trends*. University of Zambia Press.

Munroe, S. (2001). *Developing a national volunteer registry of persons with deafblindness in Canada: Results from the study, 1999 – 2001*. Port Morien, Nova Scotia: Canadian Deafblind and Rubella Association.

Riggio, M. & McLetchie, B. (Eds.) (2008). *Deafblindness: Educational service guidelines*. Chapter 5: Supportive structure and administration. Perkins School for the Blind.

Van Dijk, J. (1999). 'Development through Relationships: Entering the social world'. In *Proceedings of the Developing Through Relationships XII Dbl World Conference*.

Watters, C., Owen, M., & Munroe, S. (2004). *A study of deaf-blind demographics and services in Canada*. North York, ON: Canadian National Society of the Deaf-Blind.

Wimmer, H. & Perner, J. (1983). *Beliefs about beliefs: Representation and constraining function of wrong beliefs in young children's understanding of deception*. *Cognition* 13:103-128.

Appendices

Appendix A: Interview Guide for Teachers

Dear respondent

My name is Rachel Chomba. I am carrying out a study for Deaf-Blind International (African Researchers Initiative) on the topic Management strategies of children with Deaf-blindness in special education schools in Lusaka, Zambia. It is intended to investigate how learners are managed in the school environment. You have been selected to be one of the respondents in this research and be assured that all the information that you will give shall be treated with strict confidentiality and used for academic purposes only.

SECTION A: Biographical Information

School _____ Grades taught _____

General education qualification _____ Special education qualification _____

Years of experience in special education Years in teaching service _____

SECTION B: Questions

1. Does your school have children with deaf-blindness?

2. Can you describe what you understand by the term deaf-blindness?
3. What instructional strategies do teachers use in teaching children with deaf-blindness?
 - a. Is the teaching individualized or in group of children with other disabilities?
 - b. What are the teaching goals for children with deaf-blindness?
 - c. Is the general curriculum relevant in meeting the needs of learners with deaf-blindness?
 - d. How relevant is the curriculum in meeting the needs of learners with deaf-blindness?
 - e. Is the classroom environmentally friendly for learning to occur?
 - f. How do you ensure a successful learning environment for learners with deaf-blindness?
 - g. What specialized teaching materials and aids are used for learners with deaf-blindness?
4. What social and behavioural intervention strategies do teachers use in fostering social development and modelling behaviours of deaf-blind learners?
 - a. What school and class play activities are used that are meant to foster social interaction in deaf-blind learners?
 - b. Explain how you communicate effectively with deaf-blind learners
 - c. Do you engage learners with deaf-blindness in other extra-activities apart from learning?
 - d. What extra-curricular activities do you engage children into?
5. How parents involved in the education programs of their children with deaf-blindness?
 - a. Explain the activities that parents are involved in for the learners with deaf-blindness?
 - b. What school educational programs are there to involve parents of deaf-blind children?
6. What challenges do teachers face in managing children with deaf-blindness in school?
7. What possible recommendations can you suggest in the management of learners with deaf-blindness in school?

Thanking you for your cooperation.

Appendix B: Interview Guide for Parents

Biographical Information

Gender_____ Highest level of education_____

Occupation_____

1. When was your child diagnosed with deaf-blindness?
2. How was your child diagnosed with deaf-blindness?
3. When did your child start school?
4. How would you describe a deaf-blind child?
5. What have been the copying strategies to the condition?
6. Are you involved in the education of your child with deaf-blindness?
7. If not involved explain why you are not involved in the education of your child with Deaf-blindness?
8. If involved, how do you involve yourself in the education programs of your child with deaf-blindness?
9. Does the school provide opportunities for you to participate in the education of your child?
10. If your answer to question 9 is yes, how does the school provide opportunities for you to be involved in the child's education?
11. Does your child require special materials at school and if yes, mention which ones?
12. Does your child receive any therapy and treatment?
13. If so, what type of therapy and treatment does the child receive and from which professionals?
14. Explain how you communicate and help your child with social and language skills?
15. Do you engage the child in activities at home with siblings and peers in the community and if yes mention how?
16. What have been your challenges in managing your child with deaf-blindness at school and in the Community?

19. Do you have any challenges in managing your child with deaf-blindness at their school and if yes, mention them?
20. What possible recommendations can you make for the management of learners with deaf-blindness?

Thanking you for your cooperation.

Appendix C: Interview Guide for Headteachers

Biographical Information

School _____ Gender _____

Years in teaching service _____ Years in special education _____

1. Does your school have learners with deaf-blindness?
2. How many deaf-blind learners does your school have?
3. What measures do you put across to accommodate deaf-blind learners in the school and classroom environments?
4. Do you have qualified personnel to cater for learners with deaf-blindness?
5. Do you have adequate personnel to meet the special needs of learners with deaf-blindness?
6. Do the learners with deaf-blindness require specialized materials and if yes what type?
7. How do you help deaf-blind learners in development?
8. What school programs do you provide to deaf-blind learners that foster social development?
9. Do you involve learners with deaf-blindness in other school programs apart from classroom learning and if yes mention them?
10. Are parents involved in the education of their children with deaf-blindness?
11. How does the school involve parents in the education of learners with deaf-blindness?
12. Does the school receive funding towards special education?
13. If yes, what mechanism does the school use to allocate to children with deaf-blindness?

14. What challenges have been encountered in management of learners with deaf-blindness?

15. What possible recommendations can you make for the management of learners with deaf-blindness?

Thanking you for your cooperation

Appendix D: Observation Checklist for The School

NO.	QUESTIONS	YES	NO	DETAILED ANSWER
1	Is the learning individualized or grouped of learners with other types of disabilities?			
2	What methods of teaching are used?			
3	Are there enough teaching and learning materials for deaf-blind children?			
4	Skills and knowledge in handling deaf-blind learners?			
5	Does teacher foster language in deaf-blind learners?			
6	Does teacher manage and foster social development in deaf-blind learners?			
7	Are deaf-blind learners involved in extra-curricular activities?			
8	Do teachers face challenges in handling learners with deaf-blindness in schools?			

Thanking you for your cooperation

Natural Communication Abilities Among Children With Congenital Deafblindness in Mult-Linguistic Communities of Zambia

Brighton Kumatongo

Kitwe College of Education

Email: bkumatongo@yahoo.com

Douglas Gawani Phiri

Zambia Institute of Special Education

Email: douglasgawani25@gmail.com

Abstract

Children with Deafblindness in Zambian communities face communication challenges. Communication forms the basis for human interaction, exchange of ideas and feelings as well as facilitating inclusiveness in society. This study which is anchored on the theory of dialogism as theoretical framework, sought to assess the natural communication abilities of children with congenital deafblindness and further explore measures taken by caregiver/parents to enhance communication abilities of the children. A qualitative case study was used as research design. Snowball sampling technique was used to sample three (3) children with congenital deafblindness aged three (3), eleven (11) and twelve (12) and three (3) parents and one (1) relative who participated in the study, making the total number of (7) seven participants. The participants were from Lusaka, Copperbelt and Northwestern provinces of Zambia.

The findings were that children with congenital deafblindness were able to use natural signs to communicate their feelings of happiness, frustration or discomfort, detected sounds, expressed mistreatment and used imitations, tapping and pointing signs. The study concluded that despite children with congenital deafblindness having the ability to naturally communicate, parents 1, 2 and relative 1 had no knowledge on techniques that could enhance communication in the children, whereas parent 3 was able to communicate with her child with congenital deafblindness through the use of hand over hand communication, object of reference, body contact and hand tactile techniques. The study recommended the need to teach communication techniques to parents and caregivers of children with deafblindness in order to improve communication skills of children with deafblindness.

Background

Deafblindness is a condition in which an individual has a combination of auditory and visual impairment (Vervloed et al., 2006), which can either be congenital or acquired. Congenital Deafblindness is present at birth and covers a spectrum of combinations of varying degrees of vision and hearing loss (Deasy & Lyddy, 2009), whereas acquired deafblindness may occur after an individual has acquired some form of language later in life (Knoors & Vervloed, 2003; Vervloed et al., 2006). Studies on communication of children with deafblindness have shown that the deafblind child can use touch to communicate, interact with other people (Hersh, 2013), and may perceive the sign language tactically in monologue or dialogue conversation (Rutgersson & Arvola, 2006). Research has also revealed that some of the signs which children with deafblindness use develop naturally from their own movements and interaction with the environment (Deasy & Lyddy, 2009), whereas other signs occur due adaptations and enhancement of signs when children with deafblindness interact with their families, caregivers and teachers (Bruce, 2006; Downing & Chen, 2003). The use of natural signs and adaptations by individuals with deafblindness have been found to improve their understanding of the conceptual world, enhance their communication and creativity (Souriau, 2015; Godø, 2018; Forsgren, 2018). This study was undertaken to assess the natural communication abilities of children with congenital deafblindness and explored the measures taken by caregiver/parents to enhance communication with such children.

Statement of the problem

Despite studies showing that children with deafblindness possess natural communication abilities, parents and caregivers of children with congenital deafblindness in Zambia are not aware of how the children respond to environmental stimuli and communicate. The need to make parents and caregiver aware of the various natural responses to environment stimuli by the children with congenital deafblindness necessitated this study.

Aim of the study

The study aimed at assessing natural communication abilities of children with congenital deafblindness. The study further sought to explore the measures taken by caregiver/parents to enhance communication of children with congenital deafblindness.

Research Objectives

The study was guided by the following objectives;

- (i) To assess natural communication abilities of children with congenital Deafblindness.

- (ii) To explore the measures taken by caregiver/parents to enhance communication among children with congenital deafblindness.

Research Questions

- (i) What are the natural signs that children with congenital deafblindness use to communicate?
- (ii) What measures have caregiver/parents taken to enhance communication with children with congenital deafblindness?

Limitation of the study

The anticipated duration of this study was affected by the Corona Virus Disease (COVID-19), which led to the closure of learning institutions such as schools, colleges and universities, restricted movements, affected social interactions and subsequently making it difficult to complete the study within the stipulated time frame. COVID-19 also affected the authors and their families; hence collection of data and interaction with parents and children with deafblindness could only be done following the directives from the Ministry of Health and observations of COVID-19 health guidelines.

Generation of data on natural communication abilities of one of the children with congenital deafblindness who was exposed to various communication skills proved futile; hence the authors had to depend on information from the parent via interviews unlike video recording. The use of video recording was also restrictive in some cases due to the fact that participants' locations and recording of communication abilities could only be done after travelling to places of residence of participants. This made authors to also use semi-structured interviews as sources of information unlike solely depending on video analysis.

Theoretical Framework

The theory of dialogism by Per Linell guided this study. Dialogism is based on assumptions that human action, communication and cognition involve interactions that are interdependent and cannot be reduced to outer cause-effect relations (Linell, 2003). In reference to cognitive processes 'mind' Linell (2009) states that the human mind operates as a 'meaning-making system'; thus meaning-making facet of the mind form one of the basic principles of dialogism. The dialogical theory by Linell links cognition to communication and perceives communication and cognition as dialogically intertwined (Linell, 2003).

Theory of dialogism was chosen in that for communication to occur, cognitive structures must be active and cognitive activities can in turn produce complex linguistic activities (Linell, 2014). The theory of dialogism helped to analyse natural communication abilities of children with congenital deafblindness in this study. For instance, clapping of hands as a sign to respond to some conversations detected by a child and touching the hands of other people to report certain acts and/or initiating conversa-

tions using body touch were indications that children with congenital deafblindness attached meaning to their signs.

LITERATURE REVIEW

Acquisition of communication skills for interaction, sharing or exchange of ideas may occur naturally and/or through socialisation in children without disabilities. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) refer to communication as any verbal or nonverbal behavior, that is intentional or unintentional, likely to influence behaviour, ideas, or attitudes of another person (American Psychiatric Association, 2013). Communication thus encompasses verbal and non-verbal characteristics which require interpretation for one to comprehend the message. The type of Communication used by an individual depicts one's linguistic skills or abilities in that, language is the use of a conventional system of symbols such as spoken words, sign language, written words, and /or pictures in a rule-governed manner for communication (Kumatongo, 2019; APA, 2013). For children with deafblindness, non-verbal communication is mostly used, hence the need for parents or caregivers to be familiar with signs or forms of communication exhibited by the children with deafblindness for effective communication to occur.

Communication among individuals with Deafblindness

The human mind is viewed as having the capacity to conceive, create and communicate social reality (Marková, 2006). Individuals with visual impairment who lose hearing can still use speech for communication but require learning new modes of receiving information (American Association of the Deaf-Blind, 2015), that is if they developed speech before the onset of hearing impairment (Vervloed et al., 2006). For the deaf who become blind after acquiring skills in sign language, their communication can be mostly through sign language, though they need to learn to receive sign language through tactile (AADB, 2015). The deafblind with residual vision and hearing can still utilise their residual senses depending on environmental stimuli. If sign language is used during tactile, the person with deafblindness holds the other person's wrists and feels their movements as they sign (Hersh, 2013), the ability to interpret sign movements by the deafblind necessitates communication. Tactile signing on the palms of hands can be used to denote certain symbols for various meanings by the deafblind and in some cases signs can also be placed on the body (on body-signing) (Bonner, 2010 ; Dammeyer & Larsen, 2016). The deafblind without enough vision to perceive hand signals may perceive the sign language tactically in monologue or dialogue conversation (Rutgersson & Arvola, 2006; Dammeyer & Larsen, 2016). Both signers' hands are held under the hands of the listener in monologue conversation whereas in the dialogue position, both participants hold the right hand under the other person's left hand and the left hand on top of the other person's right hand (Rutgersson & Arvola, 2006).

The deafblind may exhibit communicative relationships such as establishing and maintaining contact, turn taking and turn giving, as well as giving feedback to and from the partner during the course of communication if their sense of touch is ef-

fectively used (Downing & Chen, 2003). Other senses can be utilised by children with deafblindness and they can also develop many gestures to express their needs (Bonner, 2010).

Communication in children with congenital deafblindness

Development of communication in children with congenital deafblindness can begin after birth and continue to improve during their daily interaction with the environment and other individuals (Damen et al., 2015). Children with congenital deafblindness develop natural signs for communication, which are gestures that come from the deafblind child's own movements (Deasy & Lyddy, 2009). The various movements made by children with deafblindness may thus depict some efforts to communicate. Expression of thoughts by individuals with deafblindness can also occur through changes in muscle tone such as tightening or relaxing of muscles (Bonner, 2010).

Communication in children with congenital deafblindness is perceived to occur at three levels referred to as; body-centered communication or communication sensory level; concrete communication or communication at a presentational level (that is the object where the communication is about is present) and the symbolic communication or communication at a representational level (Vervloed & Damen, 2016). Body-centered communication is regarded as the most basic level of communication for children with deafblindness and includes features of communication such as; laughter, crying or making vigorous body movements to show fear or excitement (Vervloed & Damen, 2015). At this level of communication, an individual is able to understand what is immediately experienced in the environment through their body and observing their bodily reactions helps to understand their feeling and what they may need (Vervloed & Damen, 2015). Effective communication at this level is therefore dependent on observation of bodily reactions of the deafblind and interpretations of the observable behaviour by individuals who intend to communicate.

Children with congenital deafblindness at concrete communication level are perceived to understand that one aspect in the world can be presented by something else, but there should be a clear connection between the form and the content (Vervloed & Damen, 2015). Dammeyer & Larsen (2016) write that using an empty drinking cup, for instance, can signal to someone at a concrete communication level that one ought to get something to drink. Individuals with deafblindness at concrete communication level are often able to learn iconic signs that are used on a regular basis such as formal signs for drinking and eating, in that such signs are similar to actual drinking and eating actions (Dammeyer & Larsen, 2016).

Enhancing communication in children with congenital deafblindness

The natural signs initiated by children with congenital deafblindness may help them to communicate with family members and other individuals in that such signs are naturally and individually motivated (Deasy & Lyddy, 2009). Despite the deafblind's ability to develop natural gestures, their communication should not be restricted to natural signs. There is need for family members and/or care givers to enhance

communication of children with congenital deafblindness. Deasy & Lyddy (2009) suggest the use of adaptive signs which are signs agreed upon by family members or individuals who work with the deafblind person. Adapted signs emerge through use by individuals who often interact with an individual with deafblindness and may differ from family to family, and can undergo modification (Deasy & Lyddy, 2009) and may make it easier for an individual with deafblindness to communicate.

The use of touch can help improve communication in children with deafblindness. Downing & Chen (2003) note that tactile enables children with deafblindness to obtain fragmented information from environment which requires an individual to put together a series of tactile impressions hence, the need to teach and improve tactile communication skills to children with deafblindness for effective communication. The use of signs and adaptations to the bodily tactile modality improves the understanding of the conceptual world of the individual child with deafblindness and also enhance communication and creativity in the symbolic use of bodily-tactile interaction (Souriau, 2015; Godø, 2018; Forsgren, 2018).

Communication in children with congenital deafblindness can also be improved by using routines. Routines or ritualised patterns may be evident in the use of sign systems by individuals who are deafblind. Deasy & Lyddy (2009) note that echolalia, in this context involves the use of signs instead of speech, and imitation rituals are commonly exhibited by individuals who are deafblind, and that such behavioural rituals may be central to their communicative efforts rather and should not be perceived as maladaptive stereotypes. An individual with deafblindness may respond not with an original response, but with the same sign that was signed to him or her. Routines within signing could be regarded as stepping stones towards developing language (Deasy & Lyddy, 2009).

Communication can also be enhanced through the use of abstract play and imitations. Bruce (2006) writes that specific developmental markers, such as abstract play, object permanence and imitation and joint attention are important for the development of symbolic communication in children with deafblindness. Enhancement of communication in children with deafblindness can be done using various modalities provided the caregivers or parents are committed and consistent.

Parents and caregivers can enhance communication in children with deafblindness through object of reference. Objects of reference are objects that refer to other objects, activities, places or people that can be used for communication purposes (Kathleen & Fiona, 2009; Blaha, 1999). An object such as a cup can be used to represent a drinking activity. The use of objects of reference can be a bridge into communicative interaction and help to support the understanding of the environment in which children with deafblindness live (Kathleen & Fiona, 2009). Tangible objects of reference can be combined with sign language to enhance communication abilities in individuals with deafblindness (Blaha, 1999). When using object of reference, a child with deafblindness may locate an object such as a cup and give it to any individual nearby to communicate the need for a drink. A piece of cloth can be used to communicate the need for clothes and touching one's stomach while displaying a relaxed face can be a way of communicating stomach pain, whereas dipping the hand of another

person in water can be used as a sign to communicate the need for bathing or swimming (Godø, 2018).

Body-with-body interaction can improve communication in children with deafblindness. Gregersen (2018) refers to body-with-body interaction as a form of togetherness in which interactions of two bodies are close and aligned with each other. For instance, the back of the child with deafblindness can be aligned with the stomach and chest of the partner. The form of togetherness created during body-with-body interaction improves perception of the partner's body in action and of the partner's emotion and motivates joint attention and subsequently improve skill acquisition by an individual with deafblindness (Gregersen, 2018).

Children with deafblindness can benefit from the use of hand-over-hand and hand-under-hand communication. Hand-over-hand and/or hand-under-hand are used to describe the hand positions of the child and the partners in their conversational interaction (Godø, 2018). The techniques can help enhance communication of children with deafblindness. The shifts between conversational hand positions indicate turn-taking and shifts between listening and talking (Godø, 2018). Reciprocity in conversation occurs when the child is able to relate what she expresses to what has been expressed by herself or the other person before and expect the other person to answer and comment her own utterance (Linell, 2009). Reciprocity in social interaction can also occur through imitation (Hart, 2006).

METHODOLOGY

The study employed a qualitative case study. A qualitative case study enables the exploration of complex phenomenon through the identification of different factors that interact with each other (Debout, 2016), thus case studies can yield intensive study of phenomena (Kumatongo & Muzata, 2021) and allow the use of multiple types of data sources and can be explanatory, exploratory, or descriptive. The study sample include; three (3) children with congenital deafblindness and three (3) parents and (1) relative, making the total number of six (7) participants. The three children with congenital deafblindness aged three (3), eleven (11) and twelve (12) years were drawn from the three provinces in Zambia namely Lusaka, Copperbelt and Northwestern provinces.

The study used snowball as sampling technique. Snowball Sampling or chain sampling is most applicable in selecting small populations that are difficult to access (Taherdoost, 2016). A researcher who employs snowball sampling technique approaches participants at a time and then ask them to refer the researcher to the other individuals (Alvi, 2016) with similar characteristics within the population, hence forming a chain or network of participants that make up a satisfactory sample of participants in the study. Snowball sampling was chosen in this study because children with congenital deafblindness were difficult to find hence, there was need to use informants to locate the children and their parents.

Semi-structured interviews were used to collect data from parents and a relative. Information from parents was collected using semi structured interviews whereas data

on natural communication abilities of children with congenital deafblindness was generated through video recording. The use of video recording helped to analyse the communication abilities exhibited by children with congenital deafblindness. Semi-structured interviews provided the basis for information from parents on how children with congenital deafblindness communicated naturally. The information generated from parents could not be captured through video recording; hence the use of semi-structured interviews was more appropriate.

Data was analysed qualitatively using video analysis and thematic data analysis techniques. The use of qualitative analysis helps to illustrate the data in great detail and deals with diverse subjects via interpretations (Neuendorf, 2019) suitable for qualitative descriptive studies. Videos captured depicting communication abilities of children with congenital deafblindness formed the source of data that was analysed via video analysis and information generated through semi-structured interviews analysed thematically based on emerging themes from the study.

Prior to undertaking this study, parents and/or caregivers of children with deafblindness were approached and explained to about the nature of the study. Consent was sought from parents or caregivers of children with congenital deafblindness who agreed to participate in the study after signing the consent forms. Confidentiality was observed to make sure that the participants in this study are not affected psychologically or otherwise. In line with maintaining confidentiality, pseudonyms were used. Informed consent was sought before interviewing participants and collecting data from children with deafblind via video recording. To ensure anonymity of participants, pseudonyms; *Smart*, *Gift* and *Joy* were used in reference to children with deafblindness who participated in the study, whereas parent 1, 2, 3 and relative 1 were used to refer to parents and one relative who participated in the study.

FINDINGS

The first objective of the study was to assess natural communication abilities for children with congenital Deafblindness. Based on this objective, the following themes emerged from the study; (1) Showing signs of happiness and excitement (2) showing signs of detecting sound (3) expressing signs of mistreatment (4) signs of frustrations (5) using tapping and pointing signs and (6) using imitations. The findings of the study were based on video analysis of *Smart*, *Gift* and *Joy* and responses from their parents during interviews.

Showing signs of happiness and excitement

Signs of happiness were expressed through smiles. One of the children identified as *Smart* could smile every time he was happy. However, differences between happiness and excitement could be detected in that excitement was characterised by efforts to stand up and start jumping or stamping the feet on the ground. If an individual perceived to be the source of excitement is closer to him, *Smart* would hug them or her tightly. In one of the recorded video which lasted for 2 minutes 36 seconds, *Smart*

was seen smiling after recognising the person and started jumping with both feet as a sign of excitement and later hugged the person.

Showing signs of detecting sounds

Smart exhibited signs of detecting sounds. During the study, it was noticed that *Smart* had residual hearing. Two different signs were used by *Smart* when detecting sounds. The first sign was the use of *index fingers*. Index fingers were inserted in both ears as signs of detecting some sounds.

The second sign could be differentiated from mere detecting sounds in that such signs indicated *Smart's* ability to detect speech and some conversations. *Smart* would “clap” his hands as a sign of detecting speech. Clapping of hands was also used as a way of trying to respond to some conversations directed to him.

In one of the recorded videos, *Smart* was seen clapping hands in the 17th second of video recording to indicate that he was able to detect sound. When contact was made with one of the researchers, *Smart* gently touched the researcher's hands and directed the hands to the ears so that the researcher could touch the ears with index fingers. The activities lasted for about 2 minutes.

Expressing signs of mistreatment

Smart was able to report some form of mistreatment. Whenever the parent punished or mistreated him, *Smart* would report the occurrence. *Smart* would touch the hands of an individual he was reporting to and guide them to his own ears and start pulling the ears upwards, an action probably used by the parent when exerting such mistreatment.

Referring to mistreatment or punishment, parent 1 said the following;

“Sometimes you have to pull his ears when he does something wrong so that he is aware of his wrong doings. My friends told me that you have to beat him a bit when he does something wrong because he may get used to doing wrong things.”

The verbatim by parent 1 above was an expression that beating or punishment was used to curb continuity of what was perceived to be bad behaviour or wrong doings by the parent. It can also be noted in the expression of parent 1 that the action taken by the parent was due to advice from friends as indicated in the verbatim above.

Expressing frustration

Expression of frustration was portrayed by *Smart* in form of throwing items given to him.

Parent 1 said the following;

“He throws anything that is given to him when he is not happy. Sometimes he even throws Nshima (Food) when he is unhappy.”

The Other sign of expressing feeling of sadness as exhibited by *Smart* was turning the face towards to wall.

“He has a tendency of facing towards the wall; sometimes he doesn’t even want to be touched.”

The response of parent 1 in the verbatim was the action exhibited by *smart* to face towards the wall as a sign of expressing frustration, because he could also refuse to be touched in some cases.

Crying was used as a commutation sign to express discomfort, frustration and attention. In one of the videos that lasted for 1minute 12 seconds, one of the children identified as *Gift* (pseudonym), was seen crying as a sign of registering displeasure. The other sign which was exhibited by *Gift* was rocking the head which seemed to be signs of maladaptive behaviour because the sign continued even when *Gift* was not showing signs of frustration or discomfort.

Using tapping, touching and pointing signs

Tapping and pointing were used by *Joy* for communication purposes. Responding to the natural communication abilities that *Joy* was using, Parent 3 said the following:

“The child would just point to the direction were the object which she wanted was kept. Sometimes she could tap your body and in some cases she would vocalised when she wanted something.”

Different ways of communication can be noted in the verbatim above as expressed by Parent 3. Pointing to the direction of an object, tapping of the body and vocalising were some ways that *Joy* could use to communicate with other people.

Touching as a means of communication was used by *Smart*. During the interview with Parent 1, the following response was provided;

“He (Smart) would touch the brother by the hand or any other person present and start pulling such a person towards the direction of the toilet.”

The response of Parent 1 is that *Smart* would initiate communication by way of touching and direct the person towards the direction of the toilet. Tactile was used alongside actions such as pulling a person towards the direct of an object.

Communication through imitations

Imitations were used as a natural means of communication by *Joy*. With reference to natural communication abilities, Parent 3 said the following:

“Sometimes she would imitate those things that I was doing. She would imitate what I would do by repeating them maybe two, three times. For instance, pointing to the food with index finger and touch her mouth to indicate that she wants to eat.”

The response from Parent 1 in the verbatim above is that imitations and repetitions were used by *Joy* to communicate. It can also be noted that from the parent’s expression, indexing and touching of objects were part of means of communication used by *Joy*.

Measures taken by parents/caregivers to enhance communication with children with deafblindness

The second objective was to explore the measures taken by the parents to enhance communication with their children with congenital deafblindness. Based on this objective, the findings included the following; (1) Use of routines (2) Using body contact (3) Using object of reference (4) using hand-over-hand communication, (5) hand tactile sign language communication and (6) observation of body language.

Using routines to enhance communication

Routines were used by relative 1 to enhance communication with *Smart*. Responding to the question on measures put in place to enhance communication with the child. Relative 1 said the following;

“In the past, he (Smart) used to mess up himself with faecal matter because we did not know what to do. We started touching him by the hand and directing him to the toilet after every meal...Smart reverted to what he used to do before we introduced him to ‘routines’ when he left our place because the people he was staying with didn’t know what to do”

The response by relative 1 above is that the people who started keeping *Smart* after he left Relative 1’s residence stopped following the routines of communicating to *Smart* by touching and taking him to the toilet after meals, which led to *Smart* reverting to his earlier behaviour of urinating and defecating in his pants.

Use of hand over hand communication and object of reference

Hand over hand was used by parent 3 to enhance communication with *Joy*. In a video that lasted for 4 minutes 33 seconds. Parent 3 was seen sitting with *Joy* on the same chair and *Joy* had a bowl on her laps. *Joy* reached for the bowl and started eating food with her hands after 20 seconds. Parent 3 extended her hand over and touched *Joy*’s hand so as to direct the hand to the folk. *Joy* touched the folk and used it to eat food from the bowl in the 30th second.

In the same video, communication using object of reference alongside hand over hand communication was used by Parent 3. After 4 minutes 10 seconds of recording, parent 3 guided *Joy* to sit on the chair near the dining table. Parent 3 later touched

Joy's right hand so as to direct it to an empty bowl that was on the table so that Joy could touch the bowl, the parent was also vocalising during the process. Parent 3 touched Joy's hand and thereafter touched her mouth twice while holding Joy's hand after 4 minutes 22 seconds. Joy's hand was later directed to an empty bowl after which Parent 3 made Joy touch her mouth tapping it twice making a sign of eating. An empty bowl in the video was used as a sign of an object used for serving food.

With reference to the use of object of reference, Parent 3 had this to say:

"The most type of communication I was using was object of reference. When it is time to eat, she would pick a spoon, fork or plate as a sign that she wants to eat either porridge, rice or other foods."

The sentiment by Parent 3 in the verbatim indicates that Joy was also able to initiate communication using object of reference, particularly when she wanted to eat food.

Using body contact

Body contact communication was used to enhance communication between Parent 3 and Joy. Referring to communication measures that she used to improve communication with Joy. Parent 3 had this to say:

"I would use body contact with my child, for example when bathing... I would act together with my child. I was the one who was leading more in the dressing and bathing part. I would primarily wash, pour water on the child's body and rub soap on the face, use a cloth, and then the child would follow the body movement as well as follow the actions that I was doing."

It can be noted in the verbatim that Parent 3 was able to initiate body contact communication, and while acting together with her child, the child was in turn able to follow the body movements and actions initiated by the parent.

The use of body touch was also reported as means of communication between Smart and his younger brother. Parent 1 indicated that Smart's younger brother aged 7 years who had low vision provided a channel of communication through body touch.

"In most cases, Smart depends on his younger brother because when I am out, his brother gives him things. For example Smart's brother would drink water first and later touch his elder brother and give him a cup of water to drink," said Parent 1.

Parent 1 in the verbatim above indicates that Smart's younger brother would use body touch to communicate with his brother.

Using Hand tactile

Hand tactile was used as a measure to enhance communication. In one of the videos, Joy was seen responding to hand tactile communication. The initiator of communication extended the hands to touch Joy with open palms; Joy gently touched the palms

of a person who was using tactile communication for 6 to 7 seconds. The initiator circled her hands while touching *Joy's* hands twice before tapping *Joy's* left hand against her right hand three times, the sign that made *Joy* to stand up in the 15th second and started walking. *Joy* was seen trailing the wall of the house with her left palm before entering another room where she was seen locating the position of the chair to which she sat on and folded both her legs with her hands. The video recording lasted 47 seconds.

The hand tactile technique as depicted in the 47 seconds of the recorded communication in which *Joy* was able to respond to tactile signs indicated that *Joy* was able to respond to familiar tactile communication.

Observation of body language

Communication via observation of body language was what parent 2 used. Commenting on measures taken to enhance communication in the child, Parent 2 said that:

"I try to check if there is something wrong when he (Gift) is crying. Sometimes I look at the body to see if there are signs of him being restless or touching his pants, because I don't know what else to do."

Based on the response of parent 2, it can be noted that despite the parent lacking knowledge on how to communicate with *Gift*, observation of the child's body language provided the source of information apart from crying.

DISCUSION

Children with congenital deafblindness exhibit different communication abilities. The first objective of this study was to determine natural communication abilities for children with congenital Deafblindness. The study has shown that children with congenital deafblindness can use different signs to express their emotions, initiate dialogue and show signs of detecting sounds if they have residual hearing. The findings of the study were that children with deafblindness were naturally able to express their feelings of happiness and/or frustrations. Smiling was one of the ways in which children with deafblindness were able to express happiness. Despite smiling being a natural way of expressing happiness by human beings, children with deafblindness had no opportunity to see how people in the environment express happiness, implying that smiling is a natural way of expressing happiness. Individual ways of expressing excitement were also noted in this study. Jumping and stamping the feet on the ground while smiling was particular characteristic of *Smart's* expression of excitement. It has to be noted that jumping and stamping of the feet is not maladaptive behaviour in this context, but a way of expressing joy and excitement.

The findings also revealed that children with deafblindness can create signs to communicate to others. For instance, *Smart* was able to communicate that he was able to detect sounds or some conversation by clapping hands. In Zambian societies, clap-

ping of hands is mostly used as a sign to show appreciation or respect when greeting other people. Clapping hands as expressed by *Smart* in this study had no linkage to the Zambian cultural way, but a natural ability to express his ability to detect sounds and some conversations. Just like Linell (2009) in the theory of dialogism note that the human mind operates as a 'meaning-making system', clapping hands and touching someone who draws closer and subsequently put the index fingers in *Smart's* ears was one way in which the 'mind' of *Smart* created a meaningful expression.

The study also revealed that children with deafblindness were able to show signs of unhappiness and frustration. Crying was one of the natural ways that *Gift* used to express discomfort, frustration as well as trying to seek attention. It must be noted that despite *Gift* crying most often when frustrated or seeking attention, the rocking of head which also occurred during crying can be termed 'maladaptive' in this context, in that the action of rocking head continued in one of the videos even when he was not crying. Crying is a natural means of expressing sadness, frustration and/or discomfort by children with deafblindness, just like any other individual. As earlier cited, Vervloed & Damen (2015) indicate that crying is one of the basic body-centered communication for children with deafblindness. Nevertheless, there is need to establish reason behind the crying of a child with deafblindness in that other gesture that can be used by other children without disabilities to augment their communication alongside crying may not be visible in children with deafblindness.

Throwing items and/or food as well as facing towards the wall were ways of expressing sadness by *Smart*. The study revealed that *Smart* could show frustrations by throwing items or food given to him. The behaviour portrayed by *Smart* in this context is not unique in that children are naturally likely to exhibit frustration by throwing things given to them. The study also revealed that *Smart* was able to report cases of mistreatment or punishment. Touching the hands of a listener and guiding them to his ears and pulling them upwards to indicate the treatment he received from the perpetrator, was reporting mistreatment. The action by *Smart* concur with Downing & Chen (2003) in their observation that the deafblind may exhibit communicative relationships such as establishing and maintaining contact, as well as giving feedback to and from the partner during the course of communication if their sense of touch is effectively used. In this study, *Smart* was able to naturally use touch to effectively report mistreatment or punishment.

The use of touch as a natural means of communication was also exhibited by *Joy*. The study found that *Joy* was able to combine tapping, touch, pointing and vocalising. Combination of tapping, touching, pointing and vocalising by a child with deafblindness depicts the aspect of total communication. It should be noted that *Joy* was naturally able to use the different means of communication. The actions *Joy* portrayed are in line with Bonner (2010) who observes that the deafblind are able to express their thoughts in different ways. With reference to the theory of dialogism which states that human action, communication and cognition involve interactions that are interdependent and cannot be reduced to outer cause-effect relations (Linell, 2003), the actions by *Joy* to use tapping, touch, pointing and vocalising indicate the interconnectedness of the cognitive and communication abilities.

Communication through body touch between *Smart* and his younger brother required enhancement. Despite *Smart*'s younger brother's effort to communicate to his elder brother via body touch whenever there was need to render help in the absence of the parent, the communication skills for *Smart*'s 7 years old younger brother could not improve his understanding of the conceptual world and tactile communication. If well enhanced, body touch and adapted signs can improve the understanding of the conceptual world, enhance communication and creativity in children with deafblindness (see Godø , 2018 ; Forsgren, 2018).

Communication through imitations was reported to be one of the ways that *Joy* used before she was introduced to other ways of communicating. Parent 3 reported that *Joy* used to imitate her by repeating what the mother was doing. Imitations commonly exhibited by individuals with deafblindness have been viewed as, central to their communicative efforts (Deasy & Lyddy, 2009), implying *Joy*'s natural efforts to communicate was through imitations. Imitations that are positively reinforced are likely to yield effective means for communication for children with deafblindness.

The second objective of the study was to explore the measures used by parents to enhance communication with their children with deafblindness. The findings where that routines, using body contact, object of reference, hand-over-hand and tactile sign language communication where used as measures to enhance communication with children with deafblindness.

The study established that routines alongside body touch where used to improve communication with *Smart*. Relative 1 reported that they started touching and directing *Smart* to the toilet every after meals as measures to prevent him from defecating in pants because they did not know what to do. The motive by Relative 1 to touch and direct *Smart* to the toilet in this context was toilet training, but it has to be noted that body touch was used as a way of communication. The action taken by the relative who was a caregiver depicts a routine measure that is naturally undertaken by an individual without knowledge of handling children with deafblindness. However, it must be noted that despite the routine measure reportedly to have helped improve communication with *Smart*, lack of consistence seem to have had affected the initially initiated routine, in that change of environment and caregivers affected *Smart*'s progress. It was reported that after *Smart* left relative 1's residence and went to live with other people, *Smart* reverted to his earlier behaviour of urinating and defecating in pants. Change of environment and caregivers as well as lack of consistence, thus contributed to *Smart*'s inability to master toileting skills effectively through the use of routines and body touch.

Hand over hand, object of reference and vocalisation was used by parent 3 to enhance communication with *Joy*. The study revealed that Parent 3 could use hand over hand and sometimes object of reference to communicate with *Joy* during eating time or when teaching daily living skills. Studies have shown that hand over hand and object of reference can be effective means of enhancing communication in children with deafblindness (Kathleen & Fiona, 2009; Blaha, 1999, Godø, 2018). The findings of this study concur with assertions made by other scholars on hand over hand and object of reference in that *Joy* was able to sometimes imitate communication us-

ing object of reference particularly when she needed food. The use of vocalisation alongside other means of communication by Parent 3 provided an opportunity for *Joy* to utilize residual hearing to improve speech and communication.

Observation of body language as a measure taken by parent 2 to detect signs of restlessness or discomfort in *Gift* may seem to have been effective in terms of enhancing communication to a child with deafblindness, nevertheless it has to be noted that the initiative was more of a natural phenomenon from a parent with lack of knowledge on how to respond to her child with deafblindness. The response from the mother whenever *Gift* cried and exhibited signs of discomfort eventually triggered the development of natural body movements and signs such as touching pants which to some extent was a reflection of the mind and body creating a 'meaning-making system' (see Linell, 2009) and subsequently attracting the attention of the mother. The scenario depicted by *Gift* concurs with the observation of Deasy & Lyddy (2009) that children with congenital deafblindness develop natural signs for communication, which are gestures that come from the deafblind's own movements. However, despite *Gift's* ability to make body movements that attracted the mother's attention, there was need to teach some signs to *Gift* if communication was to be enhanced.

The study also revealed that the use of body contact and hand tactile were measures taken by Parent 3 to enhance communication with the child. Body-to-body interaction has been cited as one of the techniques that improve communication in children with deafblindness (Gregersen, 2018). In this study, Parent 3 used body contact by acting together with a child during bathing, which made the child to follow the body movements of her mother and subsequently learning the bathing skills. The study also revealed that *Joy* was able to respond to hand tactile communication as depicted in one of the recorded videos that lasted for 47 seconds, *Joy* was seen to respond to the palm signs and tactile communication, an indication that *Joy* was familiar with the tactile communication that was used during the time of the conversation.

CONCLUSION

The study found that children with congenital deafblindness are able to develop signs and communicate naturally. It can be concluded that despite children with congenital deafblindness possessing the ability to naturally communicate their feelings of happiness, frustration or discomfort, showing signs of detecting sounds, expressing signs of mistreatment, using tapping and pointing signs and using imitations, parents 1, 2 and relative 1 had no knowledge on techniques that could enhance communication in children with congenital deafblindness, thus hindering advancement of their communication skills. It can also be concluded that effective use of appropriate communication techniques such as hand over hand communication, object of reference, body contact and hand tactile techniques by parent 3 was able to improve communication skills with her child.

RECOMMENDATIONS

1. There is need to teach communication techniques for individuals with deafblindness to parents and caregivers of children with deafblindness so that there is improved communication among children with congenital deafblindness in Zambia.
2. There is need to conduct studies on communication techniques used by parents and care givers to children with deafblindness in Zambian communities.

Funding

This work was supported by Dbl African Research Initiative.

Conflicts of Interest

No conflicts of interest were reported.

Acknowledgments

We would like to thank the African Research Initiative Advisory Committee (Dbl ARI AC) for approving and subsequently sponsoring this study under the first round of Dbl African Research Initiative on Deafblindness. Great thanks to Dr. Pawlos Kassu who played the role of the coach in this study. We also extend our gratitude to Mrs Simwizi and others who chose to remain anonymous for helping us trace children with congenital deafblindness in Zambia. We would also like to thank the Parents and children who participated in this study, without which the study could not have been successful.

References

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders*. (5th ed). Washington, DC: APA.

American Association for the Deaf-Blind (20015). *Facts about Deaf-Blind people*. Author

Ayiela, O. J. (2012). *Factors affecting KCPE performance of learners with hearing impairments in special schools in selected counties*. Nairobi: Kenyatta University.

Bodsworth, S. M., Clare, I. C. H., Simblett, S. K., & Deafblind, U.K. (2011). Deafblindness and mental health, psychological distress and unmet need among adults with dual sensory impairment. *British Journal of Visual Impairment*, 29, 6–26. doi:10.1177/0264619611038749

Bonner,S.(2010). *Communication Strategies for Persons with Deafblindness*. St. Louis: St. Louis Deafblind Task Force

- Bruce, S. M. (2010). Holistic communication profiles for children who are deafblind. *AER Journal*, 3, 106–114.
- Bruce, S. M. (2005). The impact of congenital deafblindness on the struggle to symbolism. *International Journal of Disability, Development and Education*, 52, 233–251. doi:10.1080/10349120500252882
- Colorado Commission for the Deaf and Hard of Hearing (2017). *Effective Communication Techniques: Interacting with persons who are deafblind* Retrieved on 8th February, 2020 from <http://www.state.nj.us/humanservices/cbvi/faq/etiquette/deafblind>
- Cowley, S.J., & Zheng, D. (2011). Rethinking language, mind, and world dialogically: Interactional and contextual theories of human sense-making. *Journal of Multicultural Discourses*, 00 (00), 114
- Cunha, C., Lourenc, o, P., Basto, I., & Bento, T. (2012). Dialogism in detail: Per Linell's Rethinking language, mind, and world dialogically and its potentials. *Culture and Psychology*, 0(0)1-10
- Damen, S., Janssen, M.J., Wied A. J. J. M. Ruijsenaars, W.A.J.J.M., & Schuengel, C. (2015). Communication between Children with Deafness, Blindness and Deafblindness and their Social Partners: An Intersubjective Developmental Perspective, *International Journal of Disability, Development and Education*, 62 (2), 215-243, DOI:10.1080/1034912X.2014.998177
- Dammeyer, J. & Larsen, F.A. (2016). Communication and language profiles of children with congenital deafblindness. *British Journal of Visual Impairment*, 34(3) 214–224
- Deasy, K. & Lyddy, F. (2009). *Exploring Language and Communication in an Individual with Congenital Deafblindness: A Case Study*. Retrieved from <https://www.google.com/url?sa>
- Debout, C. (2016). *Qualitative case study*. Retrieved from: <https://www.pubmed.ncbi.nlm.nih.gov>
- Downing, J.E., & Chen, D. (2003). Using Tactile Strategies With Students Who Are Blind and Have Severe Disabilities. *TEACHING Exceptional Children*, 36 (2), 56-60
- Forsgren, G. A.G.C. (2018). Sign Construction Based on Heightened Tactile Perception by Persons with Congenital Deafblindness. *Journal of Deafblind Studies on Communication*, 4(1)
- Godø, J. (2018). *A communicative encounter between a fluent signer and a youngster with congenital deafblindness*. Retrieved from: <https://nordicwelfare.org/en/disabili...>
- Gómez, V. P., & Romero, R. E. et al. (2004). *Deafblindness: A multidisciplinary analysis*. Madrid: ONCE.

Harmans, H.J.M. (2001). *The Dialogical self: Toward a Theory of Personal and Cultural Positioning*. Retrieved on 6th January, 2020 from <http://cap.sagepub.com/cgi/content/abstract/7/3/243>

Hart, P. (2006) *Using Imitation with Congenitally Deafblind Adults: Establishing Meaningful Communication Partnerships*, *Infant and Child Development*, 15, 263-274.

Hersh, M. (2013). Deafblind People, Communication, Independence, and Isolation. *Journal of Deaf Studies and Deaf Education*, *Empirical Article*, pp 1-18

Hodges, E.M. (2004). *Learning Styles in Deafblind Children: Perspectives from Practice*. PhD thesis: University of Birmingham

Janssen, H. (2017). Communication in the context of congenital deafblindness – ten years of study: How knowledge and practice develop. *Journal of Deafblind Studies on Communication*, 3, 117-119

Kathleen, D. & Fiona, L (2009). *Exploring Language and Communication in an Individual with Congenital Deafblindness: A Case Study*. Unpublished Research.

Knors, H., & Vervloed, M. P. J. (2003). *Educational programming for deaf children with multiple disabilities: Accommodating special needs*. In M. Marschark & P. E. Spencer (Eds.), *Oxford handbook of deaf studies, language, and education* (pp. 82–94). New York: Oxford University Press.

Kumatongo, B. & Muzata, K.K. (2021). Research Paradigms and Designs with their Application in Education. *Journal of Lexicography and Terminology*, 5 (1) 16 – 32

Kumatongo, B. (2019). *Learning of Mathematical Concepts by Learners with intellectual disabilities*. Retrieved from <https://www.Researchgate.net/publication/338527363>

Linell, P. (2009). *Rethinking language, mind, and world dialogically*. Charlotte, NC: Information Age Publishing.

Linell, P. (2003). WHAT IS DIALOGISM? *Aspects and elements of a dialogical approach to language, communication and cognition*. Retrieved from <http://www.coursehero.com/file/p4ick6r/Linell-P->

Linell, P. (2014). DIALOGICAL NOTEBOOK *Afterthoughts after Rethinking*. Retrieved from http://www.ipkl.gu.se/.../1475/1475848_163-a-dialogical-note-book.pdf

Marková, I. (2006). ON 'THE INNER ALTER' IN DIALOGUE. *International Journal for Dialogical Science*, 1(1), 125-147

Nafstad, A and Rødbroe, I (1999). *Co-creating communication: Perspectives on diagnostic education for individuals who are congenitally deafblind and individuals whose impairments may have similar effect*. Dronninglund, Denmark: Forlaget Nord-Press.

Paul, A., Das, B., & Mish, S. (n.d.). *Deafblindness*. Retrieved from http://www.researchgate.net/publication/237084824_Deafbli.

Rodbroe,I., & Janssen, M.(n.d.). *Communication & Congenital Deafblindness*. Retrieved from [http:// www.perkins.org](http://www.perkins.org) › congenital_deafblindness_freebie

Rutgersson,S. & Arvola,M.(2006). *User Interfaces for Persons with Deafblindness*. Presented at the 9th ERCIM Workshop “User Interfaces For All,” September 27 - 28 2006, Königswinter (Bonn), Germany. Proceedings published by Springer.

Souriau,J.(2015). “Blended spaces and Deixis in communicative activities involving persons with congenital deafblindness. *Journal of Deafblind studies on communication*,1:5-22

Vervloed,M.P.J., Van Dijk,R.J.M., Knoors,H.,& Van Dijk,J.M.(2006). Interaction Between the Teacher and the Congenitally Deafblind Child. *American Annals of The Deaf*, 151(3), 336-344

Vervloed, M. P.J. & Damen, S. (2016). *Language and Communication in People Who Are Deafblind*. In: Marschark, M. & Spencer, P. E. (Eds.) *The Oxford Handbook of Deaf Studies in Language*. Oxford:Oxford University Press.

Specialist Andragogy for DeafBlind (DB) Interpreter Guides

Dr Natasha Parkins-Maliko

University of the Witwatersrand, Lecturer
Email: Natasha.Parkins-Maliko@wits.ac.za
Supervisor: Dr Pawlos Kassu Abebe

List of Abbreviations

DBi	DeafBlind International
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WBU	World Blind Union
WFDB	World Federation of the DeafBlind
WASLI	World Association of Sign Language Interpreters
AFDB	African Federation of the DeafBlind
DBSA	Deafblind South Africa
WITS	University of the Witwatersrand
VIHEMA	
ISO	International Organisation for Standardization
SDG	Sustainable Development Goals
DHET	Department of Higher Education and Training
SLLM	School of Languages, Literature and Media
DPO	Disabled People's Organization
SALPC	South African Language Practitioner's Council
SALPCA	South African Language Practitioner's Council Act

Acknowledgement

This research was made possible by the generous funding of DeafBlind International (DBi).

DBi is an international not-for-profit membership organization focusing on the needs of individuals who are deafblind, their families and the professionals who provide services.

This project is one of 10 projects under the novel African Research Initiative. The research grant covers the research activities and presentation at the 1st African DBi Conference on Deafblindness scheduled to be held in Nairobi, Kenya in fall 2021.

Abstract:

Given the African context of anecdotal evidence of the non-provision of specialized formal training for deafblind interpreter-guides in higher education settings, I provide a situational analysis of 10 (ten) countries in the Southern African Development Community (SADC) region. The focus is on the status of the professionalization of deafblind interpreter guides. There is a clarion call for higher education institutions to transform its offering of epistemic knowledge to include disability actors to advance access to information as stated in the UNCRPD article 21. This article makes mention of DeafBlind (DB) persons' right to access information through an equitable communication mode of their choice. Here I pose the question: "How is the right afforded to DB persons, if interpreter-guides lack the required credentials to provide equitable access?" Following the trajectory of curriculum design principles, a training model is proposed based on andragogy principles for deafblind interpreter guides with the aim of providing a platform for the professionalization of DB interpreter-guides.

CHAPTER 1

Orientation to the Project

Specialist Andragogy for Deafblind Interpreter Guides

1.1 Background and Rationale

DeafBlind¹ persons according to the World Federation of the DeafBlind (WFDB) premier global report (2018) reflects as one of the key findings that around 0.2% of the

1 DeafBlind: WFDB defines deafblindness as a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, it affects social life, communi-

global population has severe deafblindness and that 2% of the world's population lives with 'milder forms' of deafblindness. Persons with deafblindness further reported a low quality of life and experience restrictions in participating in a wide range of activities. With reference to the situation in Africa the dire situation of deafblind persons with relation to access to information in as far as interpreters are concerned are increased in this poor resourced, developing region. Majinge and Stilwell (2013) and Bagandanshwa (2006) states that access to information is a fundamental human right that is not linked to social and physical status. The evidence in the Global report (WFDB, 2018) confirms a disability and development gap between the United Nations Convention on the Right of Persons with Disabilities (UNCRPD), the sustainable development goals (SDG's) and national legal and social instruments for the inclusion of persons with deafblindness.

The UNCRPD acknowledges the promotion and protection of the rights of persons with disabilities who require more intensive support such as persons with deafblindness. The UNCRPD article 21(a) and (b) speaks to the need for provision of trained interpreter-guides, although this is covertly stated:

"Article 21 – Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;"

The Global report highlights seven key areas namely: 1. pre-conditions for inclusion, 2. social protection, 3. education, 4. health, 5. work and employment, 6. political participation and 7. social participation. A hiatus in the supply of suitable, qualified interpreter-guides who are meant to provide access to the above mentioned seven key areas creates a dilemma to providing access. Deafblind people are affected by not being able to participate effectively, equitably and live productive lives independently. This unfavourable situation gives impetus to the focus on the situation of deafblind interpreter-guides in Africa, which this project seeks to shed light on. The Global report (2018) defines an interpreter-guide as:

cation, access to information, orientation and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as interpreter-guides, among others. (WFDB Global Report, 2018:4)

“A professional who provides communication and mobility support, including guiding and description, which is adapted to the needs of the person. Proper and appropriate communication methods are used at any given time and occasion.” (Pg 6).

In the same vein, the UNCRPD recognises a wide range of communication methods, such as tactile communication and braille, and languages, including sign languages and non-spoken languages, which may be used by persons with deafblindness. Inference can be drawn, that persons acting in the capacity of an interpreter-guide must be trained and fluent in one or more of the communication methods to enable equitable access for deafblind persons. In as far as access to interpreter-guides, the global report states support services are widely available in high-income countries which is in stark contrast to developing countries such as Africa. Specifically access to interpreter-guides is reported at 58% of high-income countries and 10 % of low and middle-income countries (WFDB, 2018).

Linking to the professional status of deafblind interpreter guides, the majority, if not all deafblind interpreter-guides in Africa can be grouped under the category of non-professional interpreters. According to Martinez-Gomes (2018: 417):

“Non-professional interpreters are individuals with a certain degree of bilingual competence who perform interpreting tasks on an ad hoc basis without [or little] economic compensation or prior specific training. Their awareness of the skills required to perform interpreting duties correctly and the ethical constraints thereto is shaped by their own intuitions and subject to expectations expressed by the parties to the encounters they mediate in.”

In addition to the above definition the second part of the role should be reflected on, that is the “guide” aspect. A sighted guide (interpreter-guide) is expected to follow basic principles when a person with vision impairment is being guided. Grip support for reliable and safe guidance is fundamental. The guide further provides information linked to the environment such as direction, changes in light conditions, surface changes, hazards and so forth. The training of such orientation or mobility assistance for deafblind persons is not offered to deafblind interpreter-guides.

Of significance to this study is the lack of awareness of deafblind interpreter-guides and their role in the communicative exchange. In this context, Martinez-Gomes, encapsulates the reality of deafblind interpreter-guides by stating: “Most often they conduct their tasks individually and in isolation, which translates to invisibility, lack of group solidarity and prestige, and lack of public credibility, even if they may receive immediate social recognition...” Martinez-Gomes (2018: 417).

The situation of deafblind persons and deafblind interpreter-guides is that of a vague phenomenon that is underexplored in a developing world context, such as Africa. This unexplored territory and anecdotal evidence contribute to the view that the profession of deafblind interpreter-guides lack professional status. With reference to professionalization, Rudvin posits that:

“Interpreting, like all professions, is thus a complex interweaving of numerous factors from different domains of the human experience...a necessity that all profes-

sions share is that of seeking recognition that empowers its members to “act professionally” based on their special expertise.” Rudvin (2018: 432).

It is evident that professional status for sign language interpreters is yet to be obtained in Africa (Parkins-Maliko, 2015). The progression towards professionalization of deafblind interpreter-guides too is a not within immediate bounds. When defining a profession, we need consider the components required to be recognized as a profession. Baxter (2011) and Monzo (2009) define the following categories that makes up a profession namely;

- a) Distinction / Exclusivity: Professionals who practice a specialized skill that is rare and which one cannot practice by merely observing;
- b) Group Identity: Professionals belong to a community of practice, that has a structured organization or grouping;
- c) Jurisdiction: The profession dominates a specific area because only these professionals have the technical and theoretical skill to perform the duties associated with the profession;
- d) Training: Professionals possess knowledge that is systematized, formalized, conveyed, applied and updated;
- e) Guidelines and Rules: The profession has a clearly articulated code of ethics;
- f) Accreditation: The profession has a recognized scheme of baseline accreditation and
- g) Credentials: This component is linked to institutional knowledge, professional practices and social perception of the various levels of qualifying criteria of a profession.

Gauging the professionalization of deafblind interpreter-guides generally is not straightforward since it presents uneven development or progress in the various components that make up a profession. One such component this project sets out to explore are the aspects of group identity, jurisdiction, training and credentialing. Based on the context explained above, it can be inferred that the professionalization of deafblind interpreter-guides is in a fluid state based on the statement by Rudvin (2018: 433): “Professional identity like all other social practices and systems, are situated in their wider social, political and cultural contexts and are constituted by many, sometimes conflicting variables.” The fluidity of the profession lays bare the challenges associated with advocating for a recognized profession. This project thus sets out to presents the intersectionality of the variables; political will, legislation, social views of deafblindness and epistemological gatekeeping that are embedded in the above loaded statement by Rudvin (2018). This project applies a lens of a progressive nature in higher education for consideration towards advancing the professional status of deafblind interpreter guides. Higher education is placed central to creating an upward trajectory that can counter the current situation of deafblind interpreter-guides.

The motivation for this study is an observed practical knowledge gap in the training and education of deafblind interpreters-guides in Africa.

1.2 Research Aim

To explore an andragogy training model for deafblind interpreter-guides in developing contexts such as Africa.

1.3 Project Objectives

- To provide a situational analysis report on the status of higher education training offerings for deafblind interpreter-guides in ten (10) African countries.
- To document the user experience and expectations of deafblind persons in as far as interpreting and access to information is concerned.
- To propose a training model in higher education for deafblind interpreter-guides with the lens of access to information for deafblind persons in developing country contexts, but specifically in Africa.

1.4 Research Questions

Primary Research Question

What is the status of professionalization of deafblind interpreter-guides in ten African countries as it pertains to group identity, jurisdiction, training and credentialing?

Secondary Research Question

How do deafblind persons themselves experience the level of service and professionalism that the deafblind interpreter-guides provide?

1.5 Ethics

Ethics clearance for this project was required since it involves human participants thus the application for an ethics was approved by the University of the Witwatersrand (Wits) non-medical ethics committee (HREC), Ethics clearance number R14/49. (Attachment A – Ethics Clearance certificate). In the invitation letter to consider participation in the study, prospective participants were assured of confidentiality and anonymity in data analysis presentation (Attachment B – Participant information sheet). The respondents were coded with research numbers. Storage and access to the data is restricted on a password protected file stored on a personal computer. Access to the raw data is only provided to the supervisor on this project. The data will be stored for a period of 5 years wherein the data collected will be used primarily for this project and subsequent formal presentations in relevant conferences. In addition, the data will be used for articles that will be published in relevant journals. Access to the data is also provided to researchers of the African Research Initiative (ARI) under DeafBlind International.

1.6 Anticipated Risks

The COVID-19 restrictions in as far as travel and human contact is legislated by various countries posed a risk to the collection of data for this project. The anticipated risks were mitigated by:

1. Obtaining clearance and relevant permits prior to travelling and
2. Conducting data collection remotely.

Deafblind communication (tactile sign language) requires touching of the hands and certain body parts such as the arm, back and leg (haptic signals), thus extra precautions was taken to ensure that initial contact between the researcher and the Deafblind informants were limited to introductions only. The subsequent interviews were conducted through interpreter-guides who is known to the deafblind respondent and who is fluent in English. The Centre for Disease control information fact sheet was shared with the participants. In addition, the national governments health departments Covid-19 guidelines was shared with the participants in each country. The World Federation of the DeafBlind (WFDB) guidance on Corona virus provisions and guidelines was also shared with the participants.

1.7 Project Funding

This project is one of 10 projects under the novel African Research Initiative. The research grant amounts to 500 Euros for the project and an additional 700 Euros to present the research at the 1st African Dbl Conference on Deafblindness scheduled to be held in Nairobi, Kenya in fall 2021.

CHAPTER 2 Methodology

2.1 Introduction

This project follows a qualitative, descriptive research frame. Studies on deafblind persons are minimal, thus studies that do include DB persons must be thorough to ensure a high level of reliability to ensure that the results are consistent over a time period and that the results are valid for the population of deafblind persons and that the sample is representative of the deafblind population. Following guidance provided by Skilton, et al. (2018), for research on deafblind persons the priority was placed on acknowledging and accommodating a range of different approaches for individual communication and accessibility needs as well as the importance of finding the right space and time to conduct the research.

This study included various deafblind persons on the full spectrum of identification of dual- sensory impairments and the inclusion of various communication methods used. The results of this study is intended to be replicated to other deafblind populations with similar demographics as the participants in this study.

A triangulation approach to collect data was followed with the following themes, namely:

1. Status (professionalization) of deafblind interpreter-guides in 10 African countries,
2. Current status of training and education of deafblind interpreter guides in 10 African countries,
3. Formal and informal training options in country (university offerings versus organizational offerings),
4. National accreditation system for credentials in provision of deafblind interpreter-guide services,
5. Legislation with reference to provision and regulation of deafblind interpreter-guides in country,
6. Higher education curriculum guidelines reflecting expected learning outcomes and required minimum skills for deafblind interpreters-guides
7. Level of interpreting service provision for deafblind persons from the deaf-blind clients' perspective.

2.2 Data Collection Tools

The data was collected through a desktop survey and a questionnaire.

2.2.1 The desktop survey was intended to source information on the following:

- Training offerings for deafblind interpreter-guides in country by public and private universities.
- Training offerings for deafblind interpreter-guides in country by organizations (organizations of and for persons with disabilities or professional associations)
- National legislation with reference to the provision and regulation of deaf-blind interpreter-guides
- National registry for deafblind interpreter-guides

2.2.2 Questionnaire (Electronic)

Questionnaires were administered online through email.

2.2.3 Questionnaire for deafblind respondents (Attachment D)

It was envisioned that the deafblind person will read the questionnaire through text to speech software (eg. JAWS) to listen to the question and respond in writing (braille keyboard) by typing their responses for those deafblind respondents who had some residual hearing. In most cases the deafblind respondent person could respond by tactile signs, finger writing on palm, tadoma and so forth, where the deafblind interpreter-guide documented the responses.

The questionnaire had two sections namely:

1. Section A: Biographical Details
2. Section B: Legislation, Training & Social Views

2.2.4 Questionnaire for deafblind interpreter-guides (Attachment E)

The deafblind interpreter-guides completed the questionnaires online through an email attachment. The questionnaire had three sections namely:

1. Section A: Biographical details
2. Section B: Interpreter related experience
3. Section C: Legislation, training & social views

2.2.5 Structured Interviews (In-person / Electronic)

Interviews were proposed at the proposal stage of this project which was to be conducted in English and or in the spoken language preferred by the respondent. Unfortunately, due to COVID-19 lockdown restrictions structured interviews could not be conducted and interviews were done online.

2.3 Sampling

Purposive sampling method was used to target specific deafblind people and interpreter-guides in ten (10) SADC countries. The contacts of the respondents were obtained from deafblind persons and organizations of deafblind persons. The African Federation of the Deafblind (AFDB) nominated specific affiliates to participate in the research. Both respondent groups were provided with participant information sheet and consent form (Attachments B, C).

The sample was drawn from the following countries where deafblind organizations and or institutions and contacts were established:

1. Botswana
2. Lesotho
3. Malawi

4. Mauritius
5. Mozambique
6. Namibia
7. South Africa
8. e-Swatini
9. Zambia
10. Zimbabwe

The criteria for participation in the study were a person who has congenital or acquired deafblindness, who is literate in the communication methods they use to communicate, based in the 10 African countries and affiliated to the AFDB.

The sample size was 10 deafblind persons from the listed countries and as identified by the AFDB. In addition, there were 10 deafblind interpreter-guides as identified by the deafblind respondents, thus the total sample size was 20.

CHAPTER 3

Data Analysis

This chapter discusses the data analysis and findings of the study.

3.1 Section A: Desk study

The desk study across the 10 countries main universities indicates that there is no offering either in a short course or degree format for deafblind interpreter-guides. BA-degree programmes, specifically in communication and interpreting and translation are offered in the faculty of humanities across most universities in the 10 countries, but they all lack the component of deafblind interpreter-guide training.

It is reported that organizations of persons with disabilities provide ad hoc workshops for deafblind interpreter-guides but these trainings or workshops does not lend to formal certification or is not recognised as formal training towards credits at higher education institutions. The following organizations provide such short course training. **note the training is not accredited and does not hold any credits*

African Federation of the DeafBlind (AFDB)
Deaf Federation of South Africa (DeafSA)
WITS Centre for Deaf Studies (CFDS)
Kyambogo University
Kenyatta University

Table 1: Organizations providing training for deafblind interpreting

All 10 countries have national legislation that related to disability and services for persons with disabilities but none speaks to the provision and regulation of deafblind interpreter-guides. There is no formal registry of deafblind interpreter-guides across the 10 countries. For a registry to be established there must be a credentialing process which speaks to formal, accredited recognized training for deafblind interpreter-guides. Furthermore a formal registry of interpreter-guides require the passing of a bill / act / law that regulates the provision of the dual service, that of being an interpreter and a guide. In the case of South Africa, which is the only country across the ten countries with an act that relates to the regulation of language practitioners, there is a glaring gap in the statement of credentialing of deafblind interpreter-guides. The South African Language Practitioners Council (Act No. 8 of 2014), (SALPCA) aims to regulate the training of language practitioners and control the accreditation and registration of language practitioners. It must be noted that the South African Language Practitioner's Council (SALPC) is not yet fully functional. However, a working group was established to move some of the actions and the mandate of the council along.

3.2 Section B: Questionnaire Deafblind Respondent

Out of 10 respondents only 3 responded. The age range of respondents were 50-65.

All respondents were male and all 3 respondents had acquired deafblindness. They had loss their hearing gradually thus deafness is the primary disability and later lost their vision. All 3 respondents have varying degrees of functionality related to their deafblindness depending on the severity of deafblindness and the impact on their independent living.

All 3 respondents confirm that they are aware of the UNCRPD on a global level but is not aware of deafblind specific reference in local disability policies in the South African, Malawian and Zambian context. They also shared that they were not aware of formal training provided for deafblind interpreter-guides in these three countries.

All 3 respondents painted a bleak picture related to social views of deafblind persons. In South African, Malawi and Zambia deafblindness is seen as an illness following the medical classification of deafblindness. The human rights approach to engage with deafblind persons is disregarded. Social stigma thrives in communities where deafblindness is seen as a curse and is associated with witchcraft. Deafblind persons are viewed as incapable of independent living and are mostly cared for by their immediate family members. Institutionalization of deafblind persons is on the increase where they are referred to institutions for care if and when the family cannot cope with their care needs.

3.3 Questionnaire deafblind interpreter

Out of the 10 interpreters only 6 responded to the questionnaire. These respondents represented the following countries: South Africa, Malawi, Zambia, Zimbabwe,

Mozambique and Lesotho. Their age categories are between 25 and 55. With regards to qualifications, 4 had high school education, 1 had college education and 1 had a degree in Education.

On the question of training all 6 responded that they have had no formal training but rather on the job coaching when they attended a workshop or conference. This coaching was provided by other trained deafblind interpreter-guides.

Their years of deafblind interpreting experience varies between 8 to 15 years.

All interpreter respondents rated themselves poor when asked about their knowledge of the definition of deafblindness. Furthermore, they are not aware of the skills required for deafblind interpreting nor how to render a service as a guide for a deafblind person. They are all aware about an interpreters' code of ethics but have not seen one specifically for deafblind interpreters.

All respondents are not aware of their role and responsibility as an interpreter or a mobility guide and do not know how to monitor their output of the target message nor how to guide safely and effectively share environmental information. Related to haptic communication, the respondents shared that they do not know how to interpret facial expressions and other nuances of deafblind communication in a spoken language, nor the environmental information. In as far as credentialing is concerned, they do not know of any minimum requirements to practise as an interpreter-guide. Furthermore, they were not aware of any national policies or laws related to language practice except for the South African respondent who referred to the SALPCA. The respondents were not aware of any formal training for deafblind interpreter-guides but cited some informal training such as workshops related to deafblind interpreting that focus mostly on the interpreting aspect and not mobility aspects of guiding. All respondents were not aware of a national registry for interpreter-guides and what it requires. The respondents expressed a similar view that deafblind persons are not treated fairly and are seen as mental health patients rather than recognition of their dual disability.

The above responses is an indication of the overall lack of recognition of deafblind people as well as their interpreter-guides.

CHAPTER 4

TRAINING MODULE FOR DEAFBLIND INTERPRETER-GUIDES

4.1 Introduction

Based on the analysis of the data collected a training module for deafblind interpreter-guide in developing settings is proposed but specifically for the African context. The model consist of andragogy principles as it pertains to realignment of curriculum in higher education to bridge the ontological and epistemological divide. It is anticipated that the training model will provide a foundation for consideration of the introduction to formal training of deafblind interpreter-guides in higher educa-

tion institutes in Africa with the aim of progressing the professionalization of African deafblind interpreter-guides.

In principle the training model is embedded in a module which specifically addresses issues related to deafblind interpreter-guide aspects and is aimed at forming part of an already accredited interpreting qualification offered at the University of the Witwatersrand. The module thus stands as an elective with specified credits.

4.2 Defining Andragogy

The study of adult learning, andragogy, has emerged as a learning framework due to its increasing popularity. The word andragogy stems from the Greek word andragogos which means “teaching adults.” (Knowles, 1980).

Knowles (1980) initially based the andragogical model on four pillars namely:

1. learner’s self-directedness,
2. learners’ accumulated and growing experience for learning
3. learners’ readiness to learn, and
4. educational shift from subject-centeredness to performance centeredness.

The incorporation of adult learning theory in deafblind interpreting-guide teaching and learning is acknowledgement of the adult learner’s previous experience, which is the case for most deafblind interpreter-guides. Deafblind interpreter-guides already actively interpret for their deafblind clients, thus have a practical orientation based on ontological knowledge of the interpreting and guide service.

The key tenet of andragogy is that adults and children have different learning traits and characteristics (Merriam & Brockett, 2007). These differences affect the processes of both the curriculum and the instruction in a significant way. Whereas the larger context of andragogy is adult education, the immediate context is adult learning. Adult education, a branch of education, refers to any “practice in which adults engage in systematic and sustained learning activities in order to gain new forms of knowledge, skills, attitudes, or values” (Merriam & Brockett, 2007). The immediate context of andragogy is adult learning or how adult learners acquire, adopt and transform the knowledge, skills, attitudes, or values provided for by the education. This context is applicable to deafblind interpreter-guides, who as previously stated, enters the training with an already established schema on and of deafblindness.

4.3 Deafblind interpreting module

The conceptualization of a training module that focus exclusively on deafblindness is layered and must be contextualised to each higher education academic approval protocols.

Online learning has become one of the most popular educational alternatives to meet the demands of today's global knowledge economy. In principle, it is recommended that the module be structured in such a way that it can be presented via distance learning (online) and in-contact. The ideal is to have a hybrid offering where the course is presented part online and part in contact to allow for practical mentoring of learners.

According to Knowles, Holton and Swanson (2014), the design of simulated or real activities that nurture opportunities to discover awareness of online activities. In this context it is critical that formative assessments are designed in a practical context where the learner engages with the theoretical components and are able to implement practically.

Another important component of the module is self- reflection in an online space. Schön (1987) proposed the notion of reflection-in-action as a practice by which a learner can make the necessary changes to existing ways of thinking to create new cognitive structures (or what he calls schema). Reflection on the process of learning creates an opportunity for the learner to combine previous experience with new learning to update or develop new schema. Sharing this reflection-in-action process between peers through an online blog can be an ideal way to amplify the benefits of this practice for all the stakeholders. Using blogs as online journals where everyone has a chance to read each other's entries is likely to increase engagement and result in an enriching learning experience

The principles of the expectancy model are critical in developing a practical orientated module that aims to deliver market-ready graduates. The components that are applicable are:

- 1. Valence that speaks to the value a learner places on the outcome of learning,*
- 2. Instrumentality that means the probability that the valued outcomes will be received given that certain outcomes are achieved and*
- 3. Expectancy which is the belief that effort will lead to outcome rewards.” (Vroom, 1995, 184).*

In the conceptualization, drafting and delivery of the training it is imperative to link the training to ontological value as it relates to the real world of interpreting and guiding aspects of deafblindness.

4.4 University of the Witwatersrand - Deafblind Interpreting (TRAN 0000)

The University of the Witwatersrand (WITS) is a public university in Johannesburg, South Africa and falls under the Department of Higher Education (DHET). WITS offers accredited qualifications. WITS is a registration of a private higher education institution as specified in the Higher Education Act (No. 101 of 1997) and therefore also deals with the requirement to register to be given the 'right to practise' as an education and training provider. The Academic Planning Office (APO) is responsible for all new course developments and as such, the proposed course on deafblind interpreting-guide is subject to the approval of this office. Once the course has been

approved by the APO the School of Languages, Literature and Media (SLLM) will host the course in the Department of Interpreting and Translation.

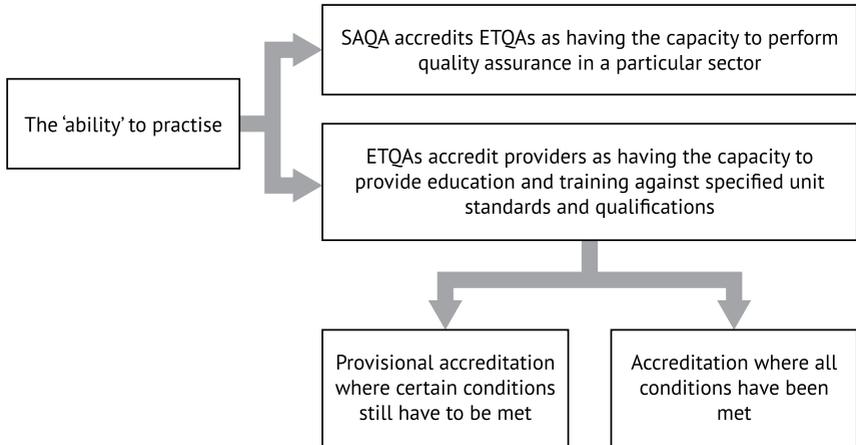


Figure 1: Accreditation of provider (SAQA, 2004).

Below is an outline of the proposed course.

4.3.1 Name and code of module

Deafblind Interpreting (TRAN 0000)

4.3.2 Qualification towards which the module can be taken

- Honours in Translation and Interpreting
- Post-Graduate Diploma in Translation and Interpreting

4.3.3 Description of the module

The aim of the module is to ensure that students receive a general orientation to deafblindness and deafblind interpreting as well as mobility orientation on guiding a deafblind person safely. Students are orientated to the concept of the course. The course objectives are clearly stated. Students are orientated on the rubric which will be used for formative assessment. Orientation is provided on the definition and categories of deafblindness. International laws and treaties related to deafblindness are discussed. Interpreting settings and modes for deafblind persons are presented. List of interpreting skills required for each setting is fledged out. The ethics of interpreting is presented based on the Demand Control Schema.

4.3.4 Learning Outcomes

After completing the course, participants will be able to:

- Convey messages accurately from one language (spoken/signed) to another in intermediate to conference and or training interpreting contexts using the deafblind interpreting mode of choice
- Use multimodal deafblind interpreting techniques appropriate for a particular context as required
- Select interpreting techniques and prioritize coping tactics in accordance with deafblind interpreting norms
- Select and demonstrate effective and safe guiding techniques
- Select and demonstrate environmental information sharing via haptic signals
- Demonstrate knowledge of legal instruments related to deafblindness
- Demonstrate knowledge of institution-related operations and procedures and knowledge schemas and the ability to compare existing knowledge schemas with current knowledge schemas in different fields and domains, e.g. Deafblind interpreting options applicable to various settings.

4.3.5 Assessment criteria for learning outcomes

The qualifying learner is able to:

- o Interpret from one language to another in deafblind interpreting contexts.
- o Application of some haptic signs (as applicable in a conference setting)
- o Set up technical equipment, prepare for conferences and manage terminology at an advanced level.
- o Use appropriate interpreting techniques and appropriate coping tactics in accordance with deafblind interpreting norms.
- o Work together with other deafblind interpreters.
- o Provide and demonstrate effective guiding techniques.
- o Understand and describe institution-related operations and procedures and knowledge schemas and compare existing and current schemas.
- o Behave in an ethical and professional manner in an interpreting context and comply with international codes of ethics.
- o Manage a team of professional deafblind interpreters when required.

4.3.6 Assessment

Feedback and assessment take place via video and/or audio files of the learner's interpretations of a number of practical source texts. Final assessment involves self-assessment of practical interpreting assignments performed by the learner in a conference and or training interpreting settings, and critical evaluation and observation of live/recorded interpretation in a conference / training interpreting setting. Evidence is submitted of effective mobility orientation and guiding of the deafblind client.

60% continuous assessment

40% final assessment/examination

4.3.7 Notional Hours

The course runs over 8 weeks (Term)

Teaching hours per week	3 hrs	8 weeks= 24
Self Study hours per week	10 hrs	8 weeks= 80
Examination hours	6 hrs	
Total notional hours		8 weeks = 110

The module is currently proposed to the APO office and thus the content of the model cannot be presented here.

CHAPTER 5

Conclusion, Limitations and Recommendations

5.1 Conclusion

This chapter focuses on the limitations of the study, state the conclusion and present recommendations.

The aim of the research was achieved by proposing a training model for deafblind interpreter-guides based on andragogy principles as fledged out in chapter 5.

The three objectives of the project were achieved. It was presented that there is a hiatus in the offering of deafblind interpreter-guide training and education modules in ten African higher education institutes. Deafblind respondents' experiences and views on interpreting and access to information was provided. Lastly a training model is proposed as a credit bearing module to be incorporated in interpreter training at higher education institutes.

The primary research question was satisfactorily answered and is at relevant for at least ten African countries. The professionalization of deafblind interpreter-guides is at a beginner phase where they are categorised as non-professionals who perform official interpreting and guide duties on an ad hoc basis without recognised nor

accredited training in deafblind settings. They perform these duties mostly without economic compensation for their services.

The secondary research question was answered in that deafblind persons appreciate the level of commitment of their dedicated and preferred interpreter-guide/s. Credentialing is important but is not a priority for them. The most critical issue raised by deafblind respondents is trust in the relationship between themselves and their interpreter-guide. Further to this, deafblind respondents point to the lack of professional engagement of interpreter-guides and raise the issue of non-payment for services which places the onus on the client to pay for the service. In most situations it is reported that the deafblind person lacks the finances to make such payment. The charity model thus prevail and the human rights model is a far fetched reality on the African context, in both public and private institutions. Reference was made to progressive international NGO's who are aware of the needs of deafblind persons and the provision for access.

5.2 Limitations

Three limitations impacted this study. First, the sample consisted of 3 Deafblind persons and 6 Deafblind interpreter guides in Africa. Therefore, the results of the study cannot be generalized to a broader population or context. The lack of responsiveness can partly be attributed to the lack of contact of the researcher with the deafblind sample group, because of the Covid-19 travel restrictions at the time.

Secondly, the health protocols of COVID-19 and lockdown restrictions impeded on the researchers' ability to travel and interview the respondents in a safe and familiar space. Therefore, the interview section of the study was not doable and this impacted the data set which was excluded in the final data analysis.

Thirdly, the response to electronic questionnaires we also impacted in that respondents either did not have access to a computer with reliable and stable internet to complete the survey, since most of them are based in rural areas. In some cases respondents simply did not have access to a device or an accessible device to participate in the study.

5.3 Recommendations

1. Contracting organizations should settle the remuneration of interpreter-guides.
2. Deafblind persons must have the authority to choose their preferred interpreter-guide
3. Deafblind interpreter-guides must undergo basic training to be functional in a high level meeting and or training.
4. Higher education institutes in Africa should consider offering a module on deafblind interpreting-guide as part of a general qualification.

5. Sensitization training for communities and political heads.

References

- Ferreira, D. & Maclean, G. (2017). *Andragogy in the 21st century: Applying the Assumptions of Adult Learning Online*.
- Knowles, M. (1980). *The modern practice of adult education: From pedagogy to andragogy*. Englewood Cliffs, NJ: Cambridge Adult Education
- Lockyer, J., Ward, R. & Toews, J. (2005). Twelve tips for effective short course design. *Medical teacher*. 27. 392-5. 10.1080/01421590500086888.
- Majinge, R. & Stilwell, C. (2013). ICT use in information delivery to people with visual impairments and in wheelchairs in Tanzanian university libraries. *South African journal of libraries and information science* 79(2): 39-50.
- Merriam, S. & Brockett, R. (2007). *The Profession and Practice of Adult Education: An Introduction*. San Francisco, CA: Jossey-Bass Publishers
- Schön, D. (1987). *Educating the reflective practitioner*. San Francisco, CA: Jossey-Bass
- Skilton, A., Boswell, E., Prince, K. et al. (2018). Overcoming barriers to the involvement of deafblind people in conversations about research: recommendations from individuals with Usher syndrome. *Res Involv Engagem* 4, 40 . <https://doi.org/10.1186/s40900-018-0124-0>
- South African Qualifications Authority (SAQA). *Criteria and Guidelines for Short Courses and Skills Programmes*. Publication date: June 2004 ISBN: 0-9584572-3-9 Accessed. April 2021. <https://www.sqa.org.za/docs/guide/2004/s-courses.pdf>
- Vroom, V. (1995). *Work and motivation*. San Francisco, CA: Jossey-Bass Publishers.

Stimulating Research in Deafblindness in Africa

Terms of Reference
ARI Advisory Committee (AC ARI)

Background

The African Researchers' Initiative (ARI) is a part of a wider initiative of DBI aimed at turning DBI into a truly global organization through diversity. The overall goal of the ARI is laying a strong foundation for knowledge based services to persons with Deafblindness in Africa by stimulating and supporting research by African researchers. The specific objective of ARI is building a network of African researchers and support ten outstanding research projects to be finished by summer 2021 and ready to be presented at the very 1st African Dbl conference on Deafblindness in fall 2021 in Kenya. ARI aims to motivate researchers in Africa to be engaged in researchers related to deafblindness. Then paves the way for the involved professionals to become members of Dbl, and create a network of African researchers who might link up or included into the Dbl Research Network. The Advisory Committee of ARI (AC ARI) is responsible for overseeing the implementation of this initiative.

Mandate of the AC ARI

The mandate of the AC ARI is building a network of African researchers, based at universities, practitioners and professionals involved in service delivery to persons with deafblindness and enabling them to conduct research and/or describe a method in working practice. The initiative runs in 2019 and 2020, and culminates in a number of abstracts and finally paper presentations at the Dbl regional conference in fall 2021 in Kenya.

Reporting Relationship

Committee members will report to the ARI coordinator who is responsible to the coordination of the overall activities of the committee. The coordinator in turn reports to the Strategic Vice President of DBI.

Roles and Activities

All Committee members will commit to:

- Actively take part in online discussions including email and video or teleconference

- Agree to share in the coordination of and/or offer support to the work of the advisory Committee
- Contribute planning and other relevant resources in order to effectively implement the work plan
- Evaluate abstracts, draft research reports or completed research reports assigned to them and provide feedbacks
- Identify obstacles and bring forward ideas and solutions
- Meet all timelines as set out in the committee's work plan
- Diligently promote and advance strategic objectives of ARI

Terms of Committee Membership

Committee members shall remain active members until the execution of the first conference on Deafblindness to be held in Nairobi, Kenya in the in fall 2021.

Meetings and General Decorum

Manner and dates of meeting will be determined by the committee members. Meeting days and times, meeting agenda as well as possible changes will be announced by the coordinator of ARI at least a week in advance. A quorum for the purposes of holding an online meeting will be the presence of four out of five members. Under normal practice, the Advisory Committee will strive to reach decisions by consensus. When necessary a vote will be taken with decisions made on the basis of three out of five. The coordinator will be responsible for documenting minutes and making them available to all committee members within five working days after the meeting. The Terms of Reference for the Advisory Committee will be reviewed if three out of the five committee members requested.

Responsibilities of Scientific Committee:

- Develop research themes and anticipated outcomes,
- Develop and implement procedures and requirements for abstract submission
- Develop and implement Criteria for abstract and final research report evaluation
- Determine abstract submission, first draft submission and final research submission deadlines
- Calling for, collecting and processing abstracts
- Select ten abstracts recommend for financial support

- Provide overall technical support and guidance in the development of abstracts, conduct, evaluation and approval of ten researches

All work of the ARI advisory Committee will be consistent and in keeping with Dbl's key principles/pillars, strategic plan, etc.

Towards Equitable Access to Public Information and Communication for Persons with Deafblindness in Uganda. A Case Study of COVID-19 Information

Aniyamuzaala James (PhD)

Email; aniyamuzaala@gmail.com

1.0: Abstract:

Persons with Deafblindness face multiple barriers to information, communication, mobility, participation and others (WFDB,2018). The review of the secondary data revealed that Persons with Deafblindness were excluded in the COVID-19 responses including the provision of COVID information and communication (IDA, 2021). Persons with Deafblindness in Uganda have the right to access to Information according to Articles 21, 2 and 9 of the United Nations Convention on Rights of Persons with disabilities (UN,2006) and Article 41 of the 1995 Uganda's Constitution. However, the 2020 Persons with Disabilities Act and the 2005 Uganda's Access to Information Act do not define the information and communication accessibility requirements for Persons with Deafblindness. This research paper examined on how the government of Uganda's COVID-19 public information and communication interventions responded to the information and communication needs and requirements of Persons with Deafblindness in Uganda. This research study used the mixed research methods to collect and analysis data. The qualitative structured interviews with Persons with Deafblindness and their care takers and others. The quantitative analysis was based on the number of qualitative interviews and responses to the questions. The results shows that government did not include Persons with Deafblindness in the design, delivery and evaluation of the COVID-19 Public information and communication interventions. The research paper recommends development of a national accessibility guide to define the accessibility requirements and specifications for access to information and communication and inclusion of Persons with Deafblindness.

2.0: Introduction:

The review of the secondary data revealed that approximately 2% of the global population or 155 million people were Persons with Deafblindness according to the

World Federation of the Deafblind (WFDB, 2018). The number of Persons with Deafblindness increased with the ageing population to approximately 6% or 456 million people worldwide. The WFDB (2018) noted that Persons with Deafblindness were often misunderstood, less known and struggle to get the right support from both development and humanitarian action interventions from the states and other actors.

Persons with Deafblindness faced multiple barriers ranging from lack of support services and inaccessible information and communication and others. This resulted into their limited participation in education, employment and community activities.

3.0: The Background:

Uganda does not have an official reliable population statistic on the population of Persons with Disabilities according to the Uganda Bureau of statistics (UBOS, 2014) Uganda Population and Housing Census Report of the 2014. The population of Persons with Deafblindness above 18 years was approximately 0.01 of the 2017 national population or 411,700 Persons with Deafblindness above 18 according to Uganda Functional Difficulties Survey Report of the 2017 (UBOS, 2017). The survey report did not provide statistics of Persons with Deafblindness between ages 2-17 years. The survey report also used the Washington group set of questions on disability statistics. The short questions do not provide for gathering of data on Persons with Deafblindness (UN, 2006).

The population of Persons with mild Deafblindness and severe Deafblindness was approximately 885,000 and 88,000 Persons with Deafblindness respectively according to Sense International Uganda (2021). The limited data on Persons with Deafblindness was classified as “Data desert for persons with deafblind”, by this research paper. Persons with Deafblindness have the right to Information and communication according to Articles 21, 2 and 9 of the Convention on Rights of Persons with disabilities (UN,2006). The CRPD requires member states to ensure that they facilitate access to information and communication for Persons with Deafblindness.

The 1995 Uganda’s Constitution provides for the right of access to Information for every citizen under article 41. The section 1 of the article 41 of the Constitution states that “(1) Every citizen has a right of access to information in the possession of the State or any other organ or agency of the State except where the release of the information is likely to prejudice the security or sovereignty of the State or interfere with the right to the privacy of any other person”.The Section 2 of article 41 of the Constitution requires Parliament to enact laws that facilitates access to information for all including Persons with Deafblindness. The 2020 Persons with Disabilities Act in Uganda recognized Persons with Deafblindness as one of the categories of persons with disabilities covered by the law under schedule 11.

However the Act did not define the functional or accessibility requirements of Persons with Deafblindness that should be fulfilled to facilitate the full participation in the different life environments and wellbeing of the Persons with Disabilities. The 2005 Uganda’s Access to Information Act does not recognise the right to accessibility for Persons with Deafblindness and other categories of Persons with Disabilities.

The research report revealed that persons with disabilities were excluded in the some of the COVID-19 responses (IDA, 2021).

Based on the challenges highlighted above, this research paper examined on the COVID-19 information and communication interventions responded to the information, communication and mobility needs and accessibility requirements of Persons with Deafblindness in Uganda. The research paper tested the research theory that stated that all the government interventions and programmes including those on COVID-19 response responded to all the accessibility requirements and needs of the Persons with Deafblindness in Uganda. The case study of members of the National Association of the Deafblind Persons in Uganda (NADBU) was used by the research study. The research study examined how NADBU members accessed and used the COVID -19 information and communication provided by Government of Uganda interventions between 2020 and 2021.

This research paper examined the accessibility requirements and specifications in legislations based on the critical analysis of the 2019 European Accessibility Act and the 2021 European Telecommunications Standard Institute's standard EN 301 549 on Accessibility requirements for Information, communication and technology (ICT) products and services. Accessibility requirements for Persons with disabilities were defined as description of the needs, personal functional difficulties and environmental barriers of Persons with Deafblindness to be addressed to achieve their access, inclusion and full participation in the different life environments. The Accessibility specifications for Persons with Deafblindness were defined as descriptions of the solutions, services, products, environments, facilities and others that meets the minimum accessibility requirements for Persons with Deafblindness.

4.0: The Methodology:

The research study used the mixed research methods composed of qualitative structured interviews with Persons with Deafblindness and their care takers. The quantitative method of statistics was used with in the qualitative analysis based on the number of qualitative interviews carried out in response to the main research question. The main research question stated, "How did the government of Uganda's COVID-19 interventions cover fully and equitably the information and communication accessibility requirements of the Persons with Deafblindness in Uganda? To measure the main research questions, the following three sub research questions were developed as follow: Which Persons with Deafblindness' needs were equitably covered by the COVID-19 responses? Which information and communication accessibility solutions were used by Persons with Deafblindness in Uganda to access COVID-19 information and communication in Uganda? Which of the information and Communication accessibility solutions used to access COVID-19 information were fully funded by the government of Uganda? The equity was measured by the coverage of all information and communication accessibility requirements and needs of the Persons with Deafblindness by the Government of Uganda's COVID-19 interventions:

4.1: Research limitations:

The data was collected during the total lockdown in Uganda due to COVID-19 pandemic. The direct contact with Persons with Deafblindness was limited. The data was collected through the programme manager of the National Association of the Deafblind persons in Uganda. The researcher collected some data through short phone call interviews with Persons with Deafblindness and their Caregivers. The structured questionnaire with the short closed and open questions was sent to the manager who reached to Persons with Deafblindness and some of the caretakers in person or physically and some interviews were carried out through phone calls. All the participants who participated were compensated for their time and this made the research excises expensive. One of the members of the research team who had collected data died during the research excise period.

5.0: The Results:

The analysis and review of the empirical data revealed the following results as follow below:

1. The information and communication needs of Persons with Deafblindness were composed of the following: Accessibility services such as care takers services, tactile and sign language interpretation services. One of the Care takers stated that, "He receives information through me. We developed our means of communication through signs and touch in hand and other parts of the body. However, he lacks concentration and a concrete way of passing on information". Another research participants with moderate to severe hearing and sight loss who acquired deafblindness at the age of 3 years and lived in the rural area used care takers to access COVID-19 information through tactile sign language. She stated that, "My parent provided me with information on Covid-19 and I did not have access to information without her". This confirmed that Care takers, sign language, tactile sign language interpreters were some of the accessibility needs for persons with severe and profound hearing and sight loss. The communication to Persons with Deafblindness through touch and tactile sign language qualified as one of the accessibility requirements to be fulfilled to facilitate participation and wellbeing of the Person with Deafblindness.
2. The participants or co-researchers reported several challenges in accessing information and communication. These were composed of the following challenges; One of the research participants with mild to moderate deafblindness using sign language as a means of access to information reported that, "Some signs are not visible and sometimes the Signs we use are difficult to learn all". This implied the person needed a training for Tactile sign language. Another research participant with mild to moderate deafblindness reported that, "The printed documents are tinny and faded. The Interpreters on the Television screen appear small". These challenges confirmed that he accessibility solutions that removed the environmental barriers through the zooming of the text, magnifier and large print font size for reading the documents printed or online were some of the interventions to facilitate participation of Per-

sons with Deafblindness. The need for zooming of the interpreter on TV to be visible by Persons with Deafblindness was another accessibility need and requirement for accessing information and communication. The provision of audio description, big picture of sign language interpreters, colour contrast and large print font were some of the accessibility specifications for meeting the accessibility requirements that emerged from the interviews with Persons with Deafblindness and their care takers.

3. The persons with mild to moderate deafblindness reported using phones, smart phones, braille, hearing aids, magnifiers and tactile sign language to access information and communication on COVID-19. The research participant with mild to moderate deafblindness from Gulu lower Urban division in Northern Uganda stated that, "I use hearing aids to amplify sound to hear. I use magnifier to read information, and I use Tactile Sign Language to access information". Another person who acquired deafblindness at the age of 18 years and lived in Kampala city stated that, "Since I am partially deafblind, I access information on COVID 19 by News updates for example listening to the radio, watching television, Messages on Phone (SMS) and from people around me". The data confirmed that the accessibility needs of the Persons with Deafblindness differ from one person to another including persons with the same level of hearing and sight loss. The positive attitudinal environment with persons that support persons with deafblindness to access information was another accessibility requirements confirmed by data above.
4. The empirical data confirmed that Government did not have a national accessibility guide and standards for inclusion, full participation and provision of services to persons with Deafblindness in Uganda. This was confirmed by the representatives of the National Council for persons with Disabilities, National Association of the Deafblind Persons in Uganda (NADBU) and Ministry of Information, Communication and Technology and National Guidance. The representative of National Council for Persons with Disabilities stated that "Government does not have a specific national policy or guide on Accessibility for persons with Disabilities. However, there is a national Policy on Disability that guides the inclusion of all Persons with Disabilities including Persons with Deafblindness".
5. The accessibility or functional specifications were composed of the accessibility accommodations such as assistive technology solutions mentioned early above and accessibility services such Tactile sign language, sign language and Caretakers or support services. These were different from the specific accessibility requirements and needs. Accessibility need was referred to as the specific necessities of the person to benefit from the use goods and services and participate in different life environments. Accessibility requirements was the sum of all accessibility needs or necessities for the diverse person to benefit from the use of goods and services and participate in the different life environments.

6. The representative of Ministry of Information, communication, Technology and national guidance stated that, "The 2005 Access to Information Act does not define the accessibility requirements of Persons with Deafblindness. I am not sure whether the 2020 Persons with Disabilities Act defines the accessibility requirements for Persons with Deafblindness". These statements confirmed that 2020 Uganda's Persons with Disabilities Act does not define the functional accessibility requirements of the Persons with Deafblindness despite outlining them as one of the categories of the persons with disabilities targeted by the law. Uganda did not have regulations and standards that defined the accessibility or functional specifications for accessible and inclusive information and communication for Persons with Deafblindness in Uganda.
7. The context of the Persons with Deafblindness and the level or degree of hearing and sight loss determined the types of accessibility needs of the person. One of the research participants with severe to profound hearing loss reported receiving information late from others. One of the care takers of the persons with profound deafblindness reported that "He lacks concentration and a concrete way of passing on information". Another research participant with severe to profound deafblindness reported that "If there is no hearing person to support me, it is difficult for me to get information". The research participant with mild to moderate deafblindness reported that, "Some people who talk to me talk at a low pitch. Other people say that I pretend". This confirmed the limited awareness of the accessibility needs of persons with deafblindness in the community. The negative attitude towards persons with deafblindness in communities limited participation of the person with deafblindness in the social, economic, political and cultural development activities.
8. The representative of National Council for persons with Disabilities confirmed that the government of Uganda used the Universal design approach in the design of government programmes and policies to respond to the diverse needs of the persons with disabilities. The Convention on Rights of persons with disabilities under article 2 defined Universal design as "The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design". The CRPD further stated that "Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed". The representative of the National Association of the Deafblind persons in Uganda (NADBU) stated that "Inclusive design is the appropriate design method for inclusion of persons with deafblindness because it considers the Human diversity of persons with deafblindness and personalizes the design of products, services, facilities, environments to the needs of diverse persons with Deafblindness. It uses a one size fits one approach and expand to many." The Inclusive Design Research (IDRC-OCAD University, 2018) Institute Canada defined Inclusive Design as a design that takes into consideration Human diversity with respect to Age, ability, gender, sex, culture, race and other dimensions of the Human diversity.

5.0: The Recommendations:

1. The Government of Uganda and National Association of the Deafblind persons should develop a National Accessibility Guide for Provision of services and full participation of the persons with deafblindness in all life environments.
2. The government should review the 2020 Persons with Disabilities Act to define the accessibility requirements for Inclusion, Full Participation and provision of services to Persons with Deafblindness in all aspects of life environments.
3. The regulations for implementation of the 2005 Information Act, the Communications Act and the 2020 Persons with Disabilities Act should define the accessibility specifications for access to information and communication for Persons with Deafblindness in Uganda.

6.0: The References:

1. WFDB and Sense International, 2018, At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deaf blindness.
2. United Nations, 2006, Convention on Rights of Persons with Disabilities.
3. Uganda, 1995, The Constitution of Republic of Uganda; article 41
4. Uganda, 2005, Access to Information Act.
5. European Union, 2019, European Accessibility Act, EU Directive 2019/2019; Accessibility requirements for Products and services.
6. ETSI, 2021, EN 301549, Accessibility requirements for ICT Products and services
7. IDRC-OCAD University, 2018, what is inclusive Design, <https://idrc.ocado.ca/>
8. Uganda Bureau of Statistics (UBOS), 2014, Uganda Population and Housing Census report
9. Uganda Bureau of Statistics (UBOS), 2017, Uganda Functional Difficulties report
10. Sense International, 2021, Population of the persons with Deafblindness in Uganda.
11. The IDA, 2021, The Survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic
12. Leeds-Hurwitz, W. (2009). Social Construction of Reality. In S. Littlejohn, & K. Foss (Eds.), *Encyclopedia of Communication Theory* (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>

13. Fairclough.N 1995, Critical discourse analysis The critical study of language- London Longman, 1995 Pp 132
14. Fairclough.N, 2005, Peripheral Vision: Discourse Analysis in Organisation Studies: The Case for Critical Realism
15. Robert Yin, 2018, Case study Research.

Visual Function Among Learners With Hearing Impairment in Schools for the Deaf in Ghana: Part 1

Dr Michael Agyemang Kwarteng

Department of Optometry, Faculty of Science and Engineering, Bindura University of Science Education, Bindura, Zimbabwe;

Discipline of Optometry, School of Health Sciences, University of KwaZulu-Natal, Durban, South Africa.

Email: kwartengmichaelagyemang@gmail.com

Prof. Khathutshelo Percy Mashige

Discipline of Optometry, School of Health Sciences, University of KwaZulu-Natal, Durban, South Africa.

Email: mashigek@ukzn.ac.za

Dr Daniel Sunkwa Quarcoo Dogbe

Department of Special Education, Faculty of Education, University of Winneba, Winneba, Ghana.

Email: dsqdogbe@uew.edu.gh

Dr Samuel Kyei

Department of Optometry, Faculty of Science and Engineering, Bindura University of Science Education, Bindura, Zimbabwe;

Department of Optometry and Vision Science, School of Allied Health Sciences, College of Health and Allied Sciences, University of Cape Coast, Cape Coast, Ghana.

Email: skyei@ucc.edu.gh

Mrs Pirindhavellie Govender-Poonsamy

Discipline of Optometry, School of Health Sciences, University of KwaZulu-Natal, Durban, South Africa.

Email: pirindha@gmail.com

Funding

This study was funded by the African Researchers' Initiative (ARI) research grant, Deafblind International (DbI), Switzerland.

ABSTRACT

Objective: To assess the visual function among learners with hearing impairment in Schools for the Deaf in Ghana.

Methods: A cross-sectional descriptive study design was used to assess the distance visual acuity with the logMAR 'E' chart, and ocular integrity with an ophthalmoscope, handheld slit lamp with a 90 D lens. A demographic questionnaire and a clinical assessment form were used to collect relevant data.

Results: A total of 952 learners were examined at the Cape Coast and Jama-si Schools for the Deaf in Ghana. Their ages ranged from 6 to 42 year with the mean age as 15.52 ± 3.84 . There were more males (56.3%) than females (43.7%) in the study. Among the learners, 84.9% were Deaf followed by moderate hearing impairment (8.1%) and no hearing impairment (1.9%), among others. Also, 92.2% of the learners had normal vision, followed by moderate visual impairment (2.7%), mild visual impairment (2.6%), and blindness (2.4%). Among the learners who were Deaf (N = 808), 17 (2.1%) had mild visual impairment, 16 (1.98%) had moderate visual impairment and 11 (1.36%) were blind. The commonest ocular morbidity was refractive error (14.2%) followed by allergic conjunctivitis (4.4%).

Conclusion: The prevalence of Deafblindness and visual impairment were low among the learners. However, these learners use the same learning environment as their counterparts with only hearing impairment. Also, the provision of spectacles can reduce the prevalence of mild and moderate visual impairment since uncorrected refractive error was their primary cause.

INTRODUCTION

The majority of students who get special education in schools around the world have vision impairment, as well as other disabilities such as hearing loss and cognitive impairment, among other things (Woodhouse, Davies, McAvinchey, & Ryan, 2014). Learners' academic success is hampered by a variety of limitations for instance when a student has multiple disabilities, sometimes referred to as dual sensory impairment (Woodhouse, Davies, McAvinchey, & Ryan, 2014). It can be difficult for educators to determine the actual source of academic issues in that student (Woodhouse, Davies, McAvinchey, & Ryan, 2014). As a result of developmental delays, students with special needs are more prone than their peers in standard schools to encounter visual difficulties (Woodhouse, Davies, McAvinchey, & Ryan, 2014; Das, Spowart, Crossley, & Gordon, 2010; Ghasia, Brunstrom, Gordon, & Tychsen, 2008; Leekam, Nieto, Libby, Wing, & Gould, 2007).

A considerable prevalence (15 - 90.1%) of ocular disorder(s) has been demonstrated in children with hearing loss (Gogate, Kalua, & Courtright, 2009). Students with hearing impairment are significantly more likely than the general population to have

vision impairment (Pehere, Khanna, Marlapati, & Sannapaneni, 2019). As a result of the widespread occurrence of hearing loss in children around the world, it has been linked to ocular diseases in children (Pehere, Khanna, Marlapati, & Sannapaneni, 2019). In order to meet the needs of these pupils who have hearing impairment, a full evaluation of visual function will be required. It is likely that the majority of their caregivers and teachers are completely unaware of these students' visual requirements. A consequence of this is that some schools do not make any or only minor modifications to instructional materials in order to accommodate for poor visual function. For this reason, any difficulties in school may be related to cognitive impairment rather than vision impairment, hence, there will be no or only modest modifications to the educational program and the curriculum may become unsuccessful.

Even though Oveneri-Ogbomo et al. (2013) published a study on vision impairment among pupils with hearing impairments in Ghana's central region, no information on vision impairment among similar learners in other regions of the country has been made in literature. Moreover, due to the fact that the study was conducted over a decade ago, it is unlikely to accurately reflect the true prevalence of vision impairment among the current students involved. Determining the visual function of children with hearing problems is therefore important.

METHODS

A descriptive cross-sectional study approach was used in this investigation, which was carried out in a clinic-setting that was set up on the premises of the Cape Coast School for the Deaf and the Jamasi School for the Deaf, both located in Ghana. The study employed a non-purposive convenience sampling since the study required all the students present at the time of the study.

Inclusion and exclusion criteria

All learners at the schools for the Deaf were included whilst learners who were absent from school and unwilling to participate during the study period were excluded.

Data collection procedure

The learners were put through a series of regular tests that are performed in optometry clinics. Determination of hearing impairment was through students' medical records with the assistance of teachers. The Measuring of visual acuity was done with the Tumbling "E" distance logMAR Chart. Examination of the anterior segment was performed on each participant using a handheld slit-lamp biomicroscope. The examination of the posterior segment was conducted with a direct ophthalmoscope and slit-lamp biomicroscope with a 90 D lens.

Data analysis

Data collected was analysed using the Statistical Package and Service Solutions (SPSS) version 21. Descriptive analysis such as ranges of visual acuity, measures of central tendency for age, and frequencies for gender were performed, and the prevalence rate and causes of vision impairment and blindness.

Ethical consideration

The study was approved by the Ghana Health Service Ethical Review Committee (GHS-ERC: 006/04/21) and the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BREC/00003247/2021). The study followed the principles of the Declaration of Helsinki regarding human beings.

RESULTS

Demographics

A total of 952 learners were examined in this study. Three hundred and seventy-seven (39.6%) learners were from the Cape Coast School for the Deaf and 575 (60.4%) from the Ashanti School for the Deaf, Jamasi in Ghana. Their ages ranged from 6 to 42 year with the mean age as 15.52 ± 3.84 . There were more males (56.3%) than females (43.7%) in the study. Among the learners, 84.9% were Deaf followed by moderate hearing impairment (8.1%) and no hearing impairment (1.9%). Also, 92.2% of the learners had normal vision, followed by moderate visual impairment (2.7%), mild visual impairment (2.6%), and blindness (2.4%).

Distribution of Hearing Impairment according to Visual Impairment

The prevalence of visual impairment among learners with hearing impairment (N= 934) was 6.0% (CI: 4.56 – 7.72). Among the learners who were Deaf, 17 (2.1%) had mild visual impairment, 16 (1.98%) had moderate visual impairment and 11 (1.36%) were blind (See Table 1). Furthermore, learners with no hearing impairment recorded the highest prevalence of blindness, 10 (55.6%).

Table 1: Distribution of Hearing Impairment according to Presenting Visual Impairment

Degree of Hearing Impairment	Presenting Visual Impairment				Total (%)
	Normal	Mild	Moderate	Blindness	
None	0	1	7	10	18(1.9)
Mild	76	1	0	0	77(8.1)
Moderate	15	0	0	0	15(1.6)
Moderately Severe	5	3	2	0	10(1.1)
Severe	6	0	0	1	7(0.7)
Profound	12	3	1	1	17(1.8)

Deaf	764	17	16	11	808(84.9)
Total	878(92.2)	25(2.6)	26(2.7)	23(2.4)	952(100.0)

Ocular Morbidity among learners according to Sex

The commonest ocular morbidity was refractive error (14.2%) followed by allergic conjunctivitis (4.4%), dry eyes (2.2%), corneal opacity (1.3%), among others.

DISCUSSION

According to the findings of this study, learners with hearing impairment in Ghana have a higher incidence of ocular morbidity but a lower prevalence of refractive error compared to a similar study by Oveneri-Ogbomo *et al* (2013) in Ghana. The decrease in the prevalence of refractive error in Ghana can be linked to an improvement in public knowledge of and access to eye care services. It will be extremely beneficial if these students and their guardians participate in regular eye screening exercises and eye health promotion.

A diverse group of participants represented a wide range of ages as a result of the establishment of vocational and technical training centers at schools for students with disabilities. This is consistent with the findings of Oveneri-Ogbomo *et al* (2013) in Ghana, as well as Majekodunmi *et al* (2018) and Abah *et al* (2011) in Nigeria, who reported ages ranging from 9 to 27 years, 11 to 39 years, and 5 to 38 years, respectively. Another factor contributing to this broad range is the late reporting of learners with hearing impairment to school. The inclusion of these learners in inclusive education will help to close the gap in age. Some guardians neglect their wards and do not monitor their academic efforts because they believe that the learners are impaired and will be unable to achieve anything meaningful in life (Kwarteng, Mashige, Naidoo, Boadi-Kusi, & Govender-Poonsamy, 2021). This false idea must be disseminated to the general public through public education.

The prevalence of visual impairment in this study was 6.0%, which is lower than the 19% reported by Abikoye *et al* (2020) and the 34.6% reported by Majekodunmi *et al* (2018) in Nigeria, as well as the 7.3% reported by Oveneri-Ogbomo *et al* (2013) in Ghana. It is believed that the increased accessibility of eye care facilities in Ghana has contributed to the decrease in prevalence. The impact of eye disorders on this sample population will be mitigated through health education and promotion, as well as inexpensive health care prices.

According to the National Center for Deaf-blindness' definition of deafblindness (dual sensory loss) (2022), which can occur even when there is both mild hearing and vision loss, 56 (6.0%) of the 934 learners with hearing loss also had visual loss (dual sensory loss). This is lower than the 7% found by Aghaji *et al* (2017) in a smaller (273) sample population in Nigeria. The decrease in prevalence is due to the types of schools that participated in the studies, the sample size, and the school's contribution to the prevalence proportion. Aghaji *et al*'s (2017) study included students from

both blind and deaf schools, whereas this study only included students from deaf schools. In Aghaji et al's (2017) study, the school for the blind was responsible for the majority (15) of the 19 learners with dual sensory loss. Further studies focusing on assessing hearing impairment among learners in schools for the blind in Sub-Saharan Africa will contribute to the literature on deafblindness. Also, 1.16% of the participants (N = 952) were totally deaf and blind. These learners, despite the low rate of occurrence, do not have the educational requirements to be integrated among their peers who just have hearing impairment. To effectively educate this particular group of learners, it is necessary to analyze and meet their educational needs.

CONCLUSION AND RECOMMENDATION

The prevalence of Deafblindness and visual impairment were low among the learners. However, these learners use the same learning environment as their counterparts with only hearing impairment. Also, the provision of spectacles can reduce the prevalence of mild and moderate visual impairment since uncorrected refractive error was the primary cause.

REFERENCES

- Abah, E. R., Oladigbolu, K. K., Samaila, E., Ahmed, A. O., & Abubakar, T. H. (2011). Ophthalmologic abnormalities among deaf students in Kaduna, Northern Nigeria. *Ann Afr Med, 10*, 29-33.
- Abikoye, T. M., Aribaba, O. T., Musa, K. O., & Idowu, O. O. (2020). Prevalence and Causes of Visual Impairment among Hearing Impaired students in Lagos, Nigeria. *Int J Pediatr Otorhinolaryngol, 139*, 1100487.
- Aghaji, A. E., Bowman, R., Ofoegbu, V. C., & Smith, A. (2017). Dual sensory impairment in special schools in South-Eastern Nigeria. *Arch Dis Child, 102*, 174-177.
- Das, M., Spowart, K., Crossley, S., & Gordon, N. D. (2010). Evidence that children with special needs all require visual assessment. *Arch Dis Child, 95*, 888-892.
- Ghasia, F., Brunstrom, J., Gordon, M., & Tychsen, L. (2008). Frequency and severity of visual sensory and motor deficits in children with cerebral palsy: gross motor function classification scale. *Invest Ophthalmol Vis Sci, 49*, 572-580.
- Gogate, P., Kalua, K., & Courtright, P. (2009). Blindness in Childhood in Developing Countries: time for a Reassessment? *PLoS Med, 6*(12), e1000177.
- Hollingsworth, R., Ludlow, A. K., Wilkins, A., Calver, R., & Allen, P. M. (2014). Visual performance and ocular abnormalities in deaf children and young adults: a literature review. *Acta Ophthalmol, 92*, 305-310.
- Kwarteng, M. A., Mashige, K. P., Naidoo, K. S., Boadi-Kusi, S. B., & Govender-Poonsamy, P. (2021). The prevalence and causes of low vision and blindness among learners at the Akropong School for the Blind, Ghana. *Afr Vis Eye Health, 80*(1), a611.

- Leekam, S. R., Nieto, C., Libby, S. J., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *J Autism Dev Disord*, *37*, 894-910.
- Majekodunmi, O. I., Olusanya, B. A., & Oluleye, T. S. (2018). Pattern of ocular abnormalities among students attending schools for the hearing impaired in Ibadan, South-West Nigeria. *Niger J Ophthalmol*, *26*, 24-27.
- National Center for Deaf-blindness. (2022). *Deaf-Blindness Overview*. Retrieved from [www.nationaldb.org: https://www.nationaldb.org/info-center/deaf-blindness-overview/](https://www.nationaldb.org/info-center/deaf-blindness-overview/)
- Omolase, C., Komolafe, O. O., & Adeniji, A. (2012). Ophthalmic disorders among students of school for the deaf. *Otolaryngol Online J*, *2*, 23-41.
- Onakpoya, O. H., & Omotoye, O. J. (2010). Screening for ophthalmic disorders and visual impairment in a Nigerian school for the deaf. *Eur J Ophthalmol*, *20*, 596-600.
- Osaiyuwu, A. B., & Ebeigbe, J. A. (2009). Prevalence of visual impairment in deaf children in Benin City. *J Nig Opt Assoc*, *15*, 20-23.
- Ovenseri-Ogbomo, G. O., Abraham, C. H., & Kio, F. E. (2013). Visual Impairment and Ocular Findings among Deaf and Hearing Impaired School Children in Central Region, Ghana. *J Med Biomed Sci*, *2*(2), 16-22.
- Pehera, N. K., Khanna, R. C., Marlapati, R., & Sannapaneni, K. (2019). Prevalence of ophthalmic disorders among hearing-impaired school children in Guntur district of Andhra Pradesh. *Indian J Ophthalmol*, *67*(4), 530-535.
- Woodhouse, J. M., Davies, N., McAviney, A., & Ryan, B. (2014). Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. *Arch Dis Child*, 500-504.