



PROCEEDINGS OF THE 1ST DBI AFRICA CONFERENCE ON DEAFBLINDNESS

12TH – 14TH MAY 2022

KENYA INSTITUTE OF SPECIAL EDUCATION, NAIROBI AND ONLINE

*Deafblind Reality in Africa:
Meeting the Sustainable Development Goals –
Opportunities and Challenges*

© 2022 Deafblind International

Edited By: Philomena Tanui (PhD) and Martin Kieti

Deafblind International
Address: 50 Main St, Paris, ON N3L 2E2 Canada
Phone: +1 877 760 7439
Email: dbi-secretariat@sensity.ca
Website: www.deafblindinternational.org

TABLE OF CONTENTS

DISCLAIMER	5
LIST OF ORGANISERS AND SPONSORS	6
ACKNOWLEDGEMENTS.....	7
PREFACE.....	8
NOTE FROM THE LOCAL HOST COMMITTEE.....	9
NOTE FROM DEAFBLIND INTERNATIONAL.....	10
 DAY 1: THURSDAY, 12TH MAY 2022	 11
 SPEECH OF THE CHIEF GUEST ON THE OPENING OF THE CONFERENCE.....	 11
KEYNOTE SPEECH – “NOTHING FOR US WITHOUT US”	13
 An Analysis of Factors That Promote Transition of Learners with Deafblindness To Independent Living	19
Examining the Tactile Sign Language Used By And With The Deafblind In Ethiopia	36
COVID-19: Implications For A Deafblind Adult In Ghana	46
Natural Communication Abilities among Children with Congenital Deafblindness in Multi-Linguistic Communities of Zambia.....	57
Towards Equitable Social Protection for Persons with Deafblindness In Uganda. A Case Study of The State’s COVID-19 Interventions.....	75
Abstract:	75
Management Strategies for Children with Deafblindness in Special Education Schools in Lusaka, Zambia	80
Five Years Of Experience Delivering High Quality Teacher Training Online Education. Experiences and Tips To Share	112
 DAY 2: FRIDAY 13TH MAY 2022	 115
 KEYNOTE SPEECH - RIGHT TO EDUCATION AND TRAINING FOR PERSONS WHO ARE DEAFBLIND IN AFRICA - THE ROLE OF INSTITUTIONS OF HIGHER LEARNING AND RESEARCH.....	 115
 Establishing Minimum Standards For Inclusive Education Of Persons With Deaf- Blindness In Uganda.	120
Determining Barriers To Education And Transition Of Children Who Are Deafblind, Kwale County	127
Prospects And Challenges Of Educating A Deafblind Student In A University	133
In Ghana.....	133
Early Screening, Intervention and Transition To Inclusive Education For Children With Deafblindness And Those With Complex Disabilities In Kenya	135
Deafblind People Taking Part In Southern Africa: A Delphi Study Looking At Stakeholder Views Of AT Outcomes	138
Towards Equitable Access To Public Information And Communication By Persons With	

Deafblindness in Uganda. A Case Study Of COVID-19 Information	142
The Statement of the Problem	142
Meeting The Problem Of Affordability Of Technical Means For Communication And Access To Information	145
DAY 3: SATURDAY, 14TH MAY 2022	150
KEYNOTE SPEECH - FUTURE OF DEAFBLIND SERVICES IN AFRICA	150
Deafblind Communication Challenge in Malawi	152
How an intervention on the Tactile Bodily Modality can -improve Communication: A Case Study of a Girl with Congenital Deafblindness in Zambia.....	154
Where do we Start?	163
Visual Functioning among Learners with Hearing Impairment in Schools for the Deaf in Ghana:.....	165
LAUNCH OF THE DBI AFRICAN NETWORK.....	171
REPORT ON EXCURSION SPONSORED BY THE DBI OUTDOOR NETWORK.....	172
CONFERENCE RESOLUTION	174

DISCLAIMER

The presentations in these *Proceedings* were compiled as received from the authors. Except for minimal formatting, no material editing was done on the content of the presentations. The editors of these *Proceedings* are therefore not responsible for any errors or misstatements thereof.

LIST OF ORGANISERS AND SPONSORS

Government of Kenya
CBM Christoffel-Blindenmission Christian Blind Mission e.V.
Association for the Physically Disabled of Kenya
Kenya Institute of Special Education
Deafblind International
Tanne, Swiss Foundation for the Deafblind
African Federation of the Deafblind
World Federation of the Deafblind
Association of African Universities
Royal Kentalis
Sense International
Perkins School for the Blind
Deafblind Ontario Services
International Council for Education of People with Visual Impairment
Centre for Communication in Special Education
German Deafblind Services
Canadian Deafblind Association
The Signo Foundation

ACKNOWLEDGEMENTS

Deafblind International wishes to express its appreciation to the many individuals and organizations that made the 1st DBI Africa Conference a success. Our sincere gratitude to the Government and the people of Kenya for hosting this monumental event in the history of deafblind services in Africa.

Sincere gratitude goes to the conference sponsors whose generous financial support highly subsidized the cost of the conference, making it affordable and accessible to many people, onsite and online.

The technical assistance from the International Advisory Committee, the Local Host Committee and the numerous sub-committees, provided the necessary leadership and direction in the organizing of the conference. This leadership was critical in marketing, resource mobilization and operational strategy for the conference.

The Conference Secretariat, volunteers and conference service providers played a pivotal role in coordinating the many aspects of conference preparation and in giving participants an optimal experience before, during and after the conference.

Finally, and most importantly, to the Chief Guest, Keynote Speakers, Presenters, Exhibitors, Participants as well as Assistants to Participants with disabilities, without whose attendance the conference would not have been. Whether onsite or online, the huge participation was the ultimate success of the conference!

PREFACE

The 1st Deafblind International (DbI) Africa Conference was held from 12th – 14th May 2022 at the Kenya Institute of Special Education, Nairobi, Kenya and online. The Conference was organized by Deafblind International in collaboration with the Government of Kenya as well as organizations in Kenya and around the world working in the area of deafblindness.

With the theme: “Deafblind Reality in Africa: Meeting the Sustainable Development Goals - Opportunities and Challenges”, the Conference served as a regional platform for connecting individuals who are deafblind, their families, professionals, researchers, developers, service organizations, libraries, universities, national and international agencies and other public and private partners in the field of Deafblindness.

Over 400 people from more than thirty countries took part in the Conference, where participants had opportunities to share information, expertise and experience on deafblindness and to discuss the future of deafblindness services in Africa within the context of the Sustainable Development Goals.

The Conference is expected to contribute towards awareness among governments and other public and private institutions in Africa and around the world on Deafblindness as a distinct disability, on the need to promote the development of appropriate services through policy and practice and to focus international attention to deafblindness in Africa.

NOTE FROM THE LOCAL HOST COMMITTEE

On behalf of the host committee in Kenya, I wish to extend my warm welcome to all the participants of the 1st Deafblind International Africa Conference. As a country, we are indeed excited and honored to host this milestone event in the history of deafblindness services in Africa!

This Conference offers us the opportunity to share information, expertise and experiences on Deafblindness. It also affords us the forum to discuss the future of deafblindness services in Africa. The theme of the conference points us towards reflections on the realities of deafblindness in Africa and to consider the opportunities and challenges towards sustainable improvement of services for persons who are deafblind in the continent.

We believe that this conference will live up to its goals of increasing awareness and recognition of Deafblindness as a distinct disability, and on the challenges faced by persons who are deafblind in Africa; improving educational, rehabilitation and transition programs for persons who are deafblind in Africa; increasing regional and international collaboration on the provision of services and exchange of information on deafblindness; and, enhancing promotion of the rights of persons who are deafblind and their inclusion in all aspects of development.

I take this opportunity to express my sincere appreciation to Deafblind International for identifying the need for an African Conference on Deafblindness and for trusting Kenya to host the Conference. I also wish to thank the International Advisory Committee for the guidance and support; our sponsors for the generous contributions towards the conference; and, all our local teams for their able planning and organizational work.

Finally, and most importantly, I wish to thank you, our Guests, Key Note Speakers, Session Moderators, Exhibitors, Participants and everyone; without you this Conference would not be a reality. Whether you are participating onsite or online, we wish you an enjoyable, fulfilling and rewarding 1st DBI Africa Conference.



David Munyendo
Country Director, CBM Kenya
Chair of the Local Host Committee

NOTE FROM DEAFBLIND INTERNATIONAL

Very welcome to the 1st DBI Africa Conference or: KARIBU!

It is indeed a pleasure to welcome you. And it is a decisive milestone to have this conference.

This conference has the great potential

- to raise awareness and inform about the situation and the needs of persons with deafblindness, especially in Africa
- to showcase the talents and the many successes achieved so far, especially in Africa, and therefore invite and inspire to further investments that will promote the rights of persons with deafblindness and their inclusion that will benefit the quality of services for all in the countries
- to learn from exciting new research and practical workshops and especially from exchange with one another
- to connect and establish sustainable networks and communities of practice, maybe leading even to a new Dbl Africa Network, a next conference and much more coordinated action

So, let us benefit from this conference - including the results of Dbl's African Researchers' Initiative. Let us also enjoy and celebrate this conference and then go into the future stronger.

DbI thanks all the individuals, organizations and sponsors involved without whom this conference would never have been possible. Asante sana!



Frank Kat
President Dbl



Mirko Baur
Strategic Vice-President Dbl,
Chair of the International Conference-Advisory

DAY 1: THURSDAY, 12TH MAY 2022

SPEECH OF THE CHIEF GUEST ON THE OPENING OF THE CONFERENCE

HON. DR. LINA JEBII KILIMO
CHIEF ADMINISTRATIVE SECRETARY
MINISTRY OF PUBLIC SERVICE, GENDER, SENIOR CITIZENS AND SPECIAL PROGRAMMES,
KENYA

Distinguished Guests, Ladies and Gentlemen,

Today we gather here from different parts of the country to discuss the future of deaf-blindness services in Africa within the context of the Sustainable Development Goals.

The Constitution of Kenya 2010 expresses the commitment to all Kenyans to nurture and protect the well-being of the individual, the family, communities and the nation. It further recognizes their aspiration for a government that is based on the essential values of human rights, equality, freedom, democracy, social justice and the rule of law.

The Constitution further requires the state to promote the development and use of indigenous languages, Kenya Sign Language, Braille and other communication formats and technologies used by persons with disabilities. These include specialized communication methods and technologies used by persons who are deafblind.

Just yesterday 11th May 2022, the Government of Kenya launched braille version guide on understanding adolescence, not to mention the media channels have a language interpreter.

In our endeavor to guarantee the rights to education and training for persons who are deafblind, the government has prioritized the provision of appropriate resources for learners with deafblindness. These include allocation of the highest capitation grants to schools for learners with deafblindness that is significantly higher than that allocated for learners with other disabilities. In addition, the government continues to support the training and deployment of qualified teachers for learners who are deafblind with the aim of attaining a ratio of one teacher per learner. The two-year diploma course for teachers of learners who are deafblind here at KISE as well as other academic and research programs at Maseno University and other similar institutions contribute specially towards the creation of human resources and knowledge to promote the education of learners who are deafblind.

Kenya has adopted a Competency-Based Curriculum that recognizes learners with special educational needs as an integral part of the education system. An educational and training pathway has been developed for the learners that cannot follow the mainstream curriculum and adapted learning materials are continuously being developed as the curriculum is rolled out. Currently, we are working on repealing the Disability Act of 2003 and has gone through the second reading in parliament so as to comply with the new Constitution of Kenya 2010.

(In the rule of law special slots for persons with disability in all levels of employment, political

representation, policy and decision-making spheres.)- In the spirit of the global clarion call of “leaving no one behind”

Distinguished Participants,

Today, Kenya has one special school for learners who are deafblind and five programs that integrate learners with deafblindness within mainstream schools. In addition, we have three vocational training units for deafblind adults as well as vocational programs in the integrated units to support young adults who are deafblind to transition into the world of adulthood and self-reliance.

Through the National Council of Persons with Disabilities, the government implements a robust program for the registration of persons with disabilities to enable them access government services and other benefits for persons with disabilities recognized by law (AGPO). These include tax exemption, extended retirement age, etc. The Council further supports institutions and programs for persons with disabilities and provides educational support, personal devices and tools of trade for them. Persons with deafblindness and their families are beneficiaries of these services.

I am so pleased to note that the rollout of the Council’s new registration system launched by H.E. President Uhuru Kenyatta CGH in the International Day of Persons with Disabilities on December 3, 2021 is on course. The new system captures deeper administrative data for planning purposes for the government, development agencies and other stakeholders. To continue implementing this presidential directive, our ministry through the leadership of The Cabinet Secretary Prof. Margaret Kobia EGH will engage the Ministry of Health to finalize the planned decentralization of the Director of Medical Services signature from Nairobi to the counties, bringing the disability assessment exercise closer to persons with disabilities. We will also track the review of the registration regulations to align with new disability medical assessment and categorization guidelines developed by the Ministry of Health.

Ladies and Gentlemen,

We recognize the work of non-state actors and development agencies such as CBM and Sense International who, together with other national and international partners, many of whom are represented here, continue to complement the efforts of the government services and a better future for persons who are deafblind.

In solidarity with the regional and international community, Kenya is signatory to numerous instruments that promote the rights of persons with disabilities. In particular, Kenya is a signatory to the UNCRPD and a contracting party to the WIPO Marrakesh Treaty to facilitate access to published works by persons with print disabilities.

We support the African Union’s Disability Protocol and look forward to signing it soon.

KEYNOTE SPEECH – “NOTHING FOR US WITHOUT US”

Geir Jensen
President, World Federation Of The Deafblind
Norway

The Conference Participants, Dear Friends, I'd like to send my regards and greetings from the WFDB and to congratulate you on this first DeafBlind International Africa Conference. I would like to thank you for giving me the opportunity to present this keynote speech that will be read by my interpreter. Nothing About Us Without Us, is the deafblind person's reality in Africa and around the world. I would like to thank the organizers, deafblind International, all the sponsors and collaborating partners. This is a landmark event and I hope the first of many successful conferences in the future.

My name is Geir Jensen and I am the president of the World Federation of the Deaf Blind (WFDB). WFDB is a representative organization of deafblind persons worldwide, with three regional and 75 national and associated member organizations by and for persons with deaf blindness. As a representative organization, the WFDB serves as the legitimate global voice of persons with deafblindness advocating for full and equal inclusion in all aspects of society.

The theme of my speech today is *Nothing About Us Without Us*. I am sure we are all very familiar with this phrase, a slogan, a mantra, or catch cry that is a call for action of which the disability movements have rallied behind. It has been instrumental in advocacy efforts for the negotiations on the conventions of the Rights of Persons with Disabilities. I would like to explore what this phrase means and in particular, how it applies to persons with deafblindness in Africa and around the world.

Nothing About Us Without Us was first used by the disability movements in the 1990s by Eastern European and South African disability activists. It was an instrumental slogan in the development of the Convention on the Rights of Persons with Disabilities (CRPD). This concept has now become mainstream, even if not completed or met perfectly everywhere. Even governments themselves will refer to the importance of this in principle in the elaboration of disability specific programs and when consulting with organizations of persons with disabilities.

The essential idea of *Nothing About Us Without Us* is that no policy should be decided by any representative without the full and direct participation of members of the groups affected by that policy. This is particularly important for marginalized groups such as persons with disabilities, and in particular, persons with deafblindness. Persons with deafblindness have been deprived throughout history of political, social and economic opportunities. The failure to include people with deafblindness in the development of laws and policies means that the exclusion and oppression becomes embedded into the fabric of society which is extremely difficult to change.

We must change this and rework the social fabric so that it is fully inclusive. Our goal is the full implementation of the CRPD societal transformation for the inclusion of persons with

deafblindness and participation in society on an equal basis with all others. In 2018, the World Federation of the Deafblind published a global report in which two key indicators were used as a kind of proxy to assess whether the states have taken appropriate steps to implement the CRPD provisions for persons with deafblindness. These indicators were the official recognition of persons with deafblindness as a distinct disability group and for the provision of interpreter guide services.

While there is a diverse range of advice I can give, goals of organizations of persons with deafblindness, which depend in part on different regions, regional and country circumstances, official recognition as a distinct disability and interpreter guide services are fundamental preconditions to ensure meaningful and purposeful participation in the decision-making processes on policies and programs for persons with deafblindness.

I will be referring to these two objectives and much of the content from the 2018 report today. WFDB will be publishing an updated version of that report in the near future. We hope it will serve as an invaluable guide to all stakeholders, and particularly governments on how they can better respect, protect and fulfill the rights of persons with deafblindness. The mantra that *Nothing About Us Without Us*, in the context of the CRPD negotiations, was a disability rights movement as a whole and more broadly, all persons with disabilities across the globe.

Having a unified and coordinated viewpoint across the disability rights movement is a critical factor in the success of the CRPD negotiations in ensuring a strong context which adequately reflects on the needs of the entire community. For persons with disabilities with different impairment types, and given specific attention where it is relevant, translating the slogan, nothing about us without us into human rights treaty language was smart.

The following parts of the CRPD in effect codify it as a human rights standard. In the preamble, consider that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them. In Article four of the CRPD on the general obligations in the development and implementation of legislation and policies to implement the present convention, and in other decision-making processes concerning issues relating to persons with disabilities, state parties shall closely consult with, and actively involve persons with disabilities, including children with disabilities throughout the representative organizations. Article 29 on participation in political and public life is also very much in line with the principle of Nothing about Us without Us, and in a way offers the strongest guarantee of long-term structural and societal transformation.

Moving from the statements of principle and general obligation of the CRPD for our purposes, the us in nothing about us without us is of course deafblindness. Deafblindness is often underestimated and misunderstood which contributes significantly to the many barriers faced by persons with deafblindness. Based on the Nordic definition, the WFDB defines deafblindness as a distinct disability arising from a dual sensory impairment of such severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, deafblindness affects social life communication, access to information and orientation and mobility.

Approximately 0.2% to 2% of the global population are persons with deaf blindness. Previous estimates suggested that around 0.2% of the world's population are living with deafblindness. Analysis of prevalence data in the report found that this figure ignores a vast number of people with milder forms of deafblindness who experience barriers to participation and discrimination. As such, 2% is a more accurate figure reflecting the diversity of persons with deafblindness. Each person with deafblindness connects, communicates and experiences the world differently. Persons with deafblindness constitute a diversified group with a broad experience of disability and have different support and inclusion requirements.

While deafblindness is more common among older age groups, deafblindness among children and young adults have a more pronounced impact on daily living in terms of barriers to education, barriers to employment and social participation as well as a higher risk of poverty. They are 10 times less likely to be employed than non-disabled people, and 30% less likely to be employed than persons with other types of disabilities. Children with deafblindness are seven times less likely to be in school than non-disabled children and twice less likely to be in school compared to children with other types of disabilities. Before we consider whether or not processes and policies sufficiently include persons with deaf blindness, it is necessary to consider whether or not there is enough about us at all.

The unfortunate reality in many countries in Africa and also across the world is that there is inadequate recognition and understanding of deafblindness. Persons with deafblindness are not recognized as a distinct disability group, and therefore not included in data collection. There is an almost complete absence of laws, policies and programs that address our specific needs. We are invisible, we are ignored, marginalized, hidden and excluded because deafblindness is less well known and often misunderstood. People with deafblindness struggle to obtain the right support and are often excluded from both development and disability programs.

Another recurrent issue is a non-recognition of persons with deafblindness within the disability movement itself. It is still a challenge for organizations of persons with deafblindness to secure adequate resources in many countries; both rich and poor countries. Again, a lack of official recognition deprives organizations of persons with deafblindness the necessary resources to carry out much needed awareness, racing, and advocacy work.

Persons with deafblindness in organizations of persons with disabilities often feel underrepresented and marginalized even within the disability rights movement. So, we also want to remind the disability rights movement that nothing about us without us is a principle that the movement itself must continue to strive to implement fully. Beyond the disability movement, 15 years after the adoption of the CRPD, it is timely to consider whether or not the CRPD has been a sufficient positive force for change for persons with deafblindness in Africa and around the world.

In the CRPD, there is one specific reference to persons with deafblindness in article 24 paragraph 3C on education. Establishing the obligation for states to ensure that education for persons who are deafblind is delivered in the most appropriate modes and means of

communication for the individual, there has not yet been a CRPD committee member with deafblindness. One could consider that the CRPD committee has not so far focused as much on the Rights of Persons with deafblindness as we would have hoped for. In this sense, we are underrepresented in the jurisprudence of the CRPD.

Having said that, there are references in several general comments that are worth reflecting on. In General Comment number seven, the committee reminds states of their duty to closely and timely consult and actively involve persons with disabilities through their representative organizations in the development and implementation of legislation and policies to implement the convention, and in other decision-making processes. The committee specified that state parties should ensure the close consultation and active involvement of organizations of persons with disabilities, which represent all persons with disabilities; including their other persons and guide interpreters who should be provided for differently during public debates with necessary financial resources for participation covered by the state.

In General Comment Number 2 on accessibility, the committee noted that persons with deafblindness face barriers when attempting to access information and communication owing to a lack of augmentative and alternative modes of communication. They also face barriers when attempting to access services due to prejudice and lack of adequate training of the staff providing those services. Special attention to the appropriate languages and modes and means of communication used by blind, deaf and deafblind students is required. And finally, in the general comment number four on inclusive education, the committee recognizes this as some groups are more at risk of exclusion from education than others such as persons with deafblindness.

In addition to the CRPD committee, the Special Rapporteur on the Rights of Persons with Disabilities is an important part of the international framework on the Rights of Persons with Disabilities. In 2016, the Special Rapporteur published an excellent report on the rights of persons with disabilities to participate in decision-making with two important references to deafblind persons. i), without accessible information and communication, a range of persons with different disabilities cannot effectively participate in lawmaking and policymaking. Generally, decision-making bodies and mechanisms do not ensure the availability of guide interpreter services for deafblind persons, and ii), a certain group of persons with disabilities face additional challenges to their participation in public life. They may be inadequately represented by existing representative organizations in a given country.

Accordingly, states must not only encourage and support participation of persons with disabilities from disadvantaged groups in representative organizations of persons with disabilities but also show flexibility and establish consultative mechanisms to enable the participation of all persons with disabilities. This is particularly important for persons with deafblindness. States must devise outreach strategies aimed at ensuring the participation of these groups. The broad inclusion of persons with disabilities throughout the public decision-making process is one of the most effective tools for states to develop truly inclusive and diverse societies. Although this report was published in 2016, (six years ago), we have unfortunately not seen much in the way of implementation efforts. But these

points are an excellent basis for our advocacy efforts. It is crystal clear what steps must be taken to ensure nothing about us without us.

I would like now to outline some of the most significant challenges faced by persons with deafblindness in Africa and around the world. Interpretive guides are available in only 58% of high-income countries, and 42% provide government funded Interpretive Guide services. The situation is more challenging in low- and middle-income countries. Interpretive Guide services are only provided in 10% of countries, with only one country providing governmental funding.

In low- and middle-income countries as well as some high-income nations, social protection benefits schemes tend to focus on basic poverty-related issues, and not enough to cover the extra costs related to the interpretation, mobility and other challenges. Common challenges to access both general health and rehabilitation services for persons with deafblindness include; a lack of accommodation in health facilities, particularly in terms of accessible information and alternative forms of communication, costs of accessing healthcare and a lack of knowledge and training on deafblindness among health professionals.

In Africa, and in most countries in the world, compared to people with other disabilities, persons with deafblindness are statistically less likely to be in employment, lack of interpreter guides social stigma and negative attitudes constitute a major barrier for many persons with deafblindness. In the majority of countries, children with deafblindness are statistically less likely to be in school than children with other kinds of disabilities. And there are no specific educational support programs for children and young people with deafblindness.

Ensuring the rights to political participation is arguably the key to unlocking progress for persons with deaf blindness to ensure nothing about us without us. Whilst few countries legally restrict the right to vote for persons with deafblindness, few actually provide support to enable political participation with voting ballots often being inaccessible, and lack of accessible information on policies and the electoral process. Consequently, persons with deafblindness are not adequately represented in politics at all levels, nor are our interests as we are an ignored constituency. However, there are some bright points, including from this region. I would like to end by highlighting a positive example of political participation and representation of Ms. Ann Mbugua in Kenya. This is also a way in which nothing about us without us can be used by individuals with powerful, transformative results.

The employment of political rights including the right to vote, and to be elected is an important aspect of participation in political and public life. Persons with deafblindness are often excluded from decision-making processes and positions of authority in government, the workplace and public life more generally. It is extremely rare for persons with deafblindness to stand for elections, hold office or perform public functions at any level of government. However, Ms Mbugua, a woman with deafblindness served as a member of the County Assembly for Nakuru County in Kenya from 2013 to 2017.

In Kenya, persons with disabilities are increasingly represented in both local and national public offices. This is in part thanks to legislation, which Ann sponsored and has helped

implement, which prescribes that persons with disabilities should fill 5% of all public positions. Ann has demonstrated that persons with deafblindness can engage effectively in public life and has helped break the stigma that prevents many persons with disabilities from participating in government. Globally, a vicious circle exists whereby a lack of awareness and a lack of recognition of persons with deafblindness as a distinct disability group has led to invisibility and consequently a failure of governments to recognize inclusion requirements.

Due to the specific implications of their disability, persons with deafblindness face additional barriers and require specific support, particularly interpreter services, guide services and tailored Rehabilitation Services amongst others. As these services are only available in a few countries, persons with deafblindness benefit little from development efforts, including those aimed at implementing the CRPD. And as outlined, and well-known from our national contexts and personal experiences, persons with deafblindness are still left behind in all countries all over the world.

There are three vital first steps that we could call preconditions for inclusion. These are one, adaptation of, in consultation with persons with deafblindness and their organizations, a consistent definition and measurement of deafblindness and ensuring universal and national recognition of deafblindness as a distinct disability in law, and in practice, and two, development, in consultation with persons with deafblindness and their organizations, of required support and deafblind interpretation services, and in particular interpretive guide, and adequate public funding to ensure support in education, work, and community life. Three, conduct additional research and data collection on the barriers facing persons with deafblindness, including access to health care, social participation, and wellbeing, quality of work and education. For all our work so far, we might say that the promises of inclusive equality in the CRPD of the International Human Rights Framework more broadly, and of the SDGs of leaving no one behind, have not yet become real for persons with deafblindness.

If we can assure that these three points above are done, then we can start to talk about nothing about us without us as a matter of reality and not just as an aspiration. This applies at the national, regional and international levels and in the disability movement itself. The human rights standards will then become more than just words on paper. Society can and must be transformed for the full inclusion of all persons with deafblindness now and in the future, in Africa, and around the world.

All the best for your Conference and thank you for giving me this opportunity.

An Analysis of Factors That Promote Transition of Learners with Deafblindness To Independent Living

Dr. Everline Nyokabi:
Lecturer, Maseno University, Kenya

Prof. Peter Oracha:
Professor, Maseno University, Kenya

While the general objective of educating learners with deafblindness in Kenya is to enable them develop skills for self-reliance and therefore independent living, a significant number who have left school are not independent. There is limited research on the preparedness of these learners for transition in Kenya. The purpose of this study therefore was to analyze factors promote transition of the learners to independent living. Objectives of the study were to establish: the extent of early identification and intervention of deafblindness; the role of parents in their upbringing; the extent of acquisition of relevant skills for transition to independent living; and the general provisions that promote acquisition of independent living skills.

A Descriptive Survey Research design was adopted for this study. Study area included Baringo, Kisumu and Nairobi counties. The study population comprised 38 learners with deafblindness and 35 teachers. Saturated sampling technique was used to select 33 learners and 25 teachers. Research instruments included questionnaire, interview schedule and document analysis guide. Data was analysed using frequency counts, percentages, means and themes. The study established that majority (31,94.0%) of the learners were identified with deaf blindness at the age of below 4 years however they were admitted to school at 6 years of age indicating late intervention.

Reports by most teachers (19,76.0%) indicated that the role of parents was only utility based. The extent of skill acquisition by the learners was minimal with vocational skills at (Mean=1.89) and literacy skills (Mean=1.63) being the least acquired. Majority of the teachers (18, 72.0%) 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 may inform policy on matters related to early identification, early intervention, parental involvement, skill development among teachers, curriculum differentiation for self-reliance and independent living of learners with deafblindness.

Key words:

Deafblindness, Early Identification, Assessment, Early intervention, Transition and Independent living

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 grows and learns new sets of skills Quinn (2011) observes 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.

In Kenya today, all learners including those with special are expected to transit from primary to secondary education. This is known as 100% transition policy. The SNE Policy Review Data Collection Report (2018), however observed that transition from primary to secondary school, vocational to job placement especially for learners with severe disabilities remained a major challenge. (2018) further acknowledges limited transition plans for learners with disabilities but proposes development of such plans that will guide transition of learners from primary to the right pathways as per the Competency-Based Curriculum (CBC).

Extent of Early Identification Assessment 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, those 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 has led 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.). When deafblindness is not identified early, the child is at risk of missing medical treatment that may greatly ameliorate 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.

In Kenya, Sense International launched an early intervention programme in 2017 in partnership with one hospital and three health centres. The three-year programme piloted

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.

Educational Assessment and Resource Centers (EARCs) have been set up for early identification, assessment, intervention and placement of children with special needs including the deafblind. This approach includes early identification s, sensitization, counseling and training of children with disabilities and their families, parents, teachers, local administration and others in meeting the needs of these children.). The extent to which the EARCs have promoted early identification and intervention of learners with deafblindness is however not clear.

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) in their study looked at the roles of parents as either academic related or utility related Findings showed that the parents mainly focused on the utility areas and not academic

Research has shown that parental participation in the education of their children plays a critical 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.

Although the role of parents in a child's education as an integral component to the curriculum's successful implementation has been emphasized by the Kenya Institute of Curriculum Development (Republic of Kenya, 2016) which states (1) Providing basic necessities (2) Protecting the child from physical and emotional harm. (3) Instilling and nurturing 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 and many others, it has been quite challenging because a good percentage of the children stay with their illiterate grandmothers and secondly, most schools are residential, so they don't meet their parents on a daily basis

General Provisions that Promote Acquisition of Necessary Skills for Transition

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. (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).

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 deafblindness requires individualized planning; systematic vocational assessment and vocational skills training; academic remediation where necessary as determined by the extent of disability and the individual and 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 deafblindness (Hodges, Douglas; Hewett,; McLinden, Terlektsi, Wootten, Ware, Williams, 2019) 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)

Extent of Acquisition of Necessary Skills for Transition

Appropriate education for students with deafblindness must be implemented according to individual needs and to the functional skills demands of adulthood. Functional skills are those an adult need to perform successfully in a variety of community settings. Functional living skills must be taught directly and systematically to some students 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

A review of global deafblind literature (Jaiswal, Aldersey, Wittich, Mirza & Finlayson, 2018) 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.

According to (Kenya Institute of Curriculum Development (KICD), 2013). I before transition to the next level, a learner with deafblindness 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 (Research evidence on the extent to which the learners have acquired the foregoing skills in preparation for transition to independent living is however scanty I hence the need to carry out this study.

Methodology

Research Design

Descriptive survey research designs was adopted for this study.

Study Population and Sample

The study was carried out in one school 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 30 teachers.

Research Instruments

Research instruments for this study included questionnaire for teachers and interview schedule for teachers and parents.

Validity and Reliability

Face and content validity was considered.

The reliability of the research instruments in this study was established through a pilot study involving 10 teachers and 5 learners.

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 organized 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

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 show data on the age of identification and age of admission to school of learners with deaf blindness.

Table 1: Age at Identification and Admission(n=33)

Age	Identification (f, %)	Admission (f, %)
Below 4 years	31(93.9)	2(6.0)
4-6 Years	1(3.0)	12(36.4)
After 6 years	1(3.0)	19(57.6)
TOTAL	33	100

Tables 1 shows 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 as the learners are past the critical age of language acquisition. Since Language and cognition are related, there is a likelihood of the learners lagging behind in cognitive development and other developmental milestone.

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

Reponses 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 absentism; Curriculum limitations 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 skill 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 9

“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 for example. On pupil- teacher ratio for learners with unique and varied need like the deafblind.”

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 the learning their children's learning process. This was further supported by 19(76.0%) of the teachers who re 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 the responses 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 2,3,4,5,6,7 and 8.

Table 2: Extent of Acquisition of Skills Necessary for Transition to Independent Living (n=33)

Skill	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 2 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.

Low level acquisition of vocational skills limits the opportunities for learners with deafblindness upon transition in terms of further skill development, job opportunities, independence in life and becoming productive members in the in the society. Extent of acquisition of independent components of the skill. The data is presented in Tables 3, 4,5,6, 7 and 8.

Table 3: Extent of Acquisition of Daily Living Skills(n=33)

Skill	Mean	Standard Deviation
Dressing	3.00	1.17
Personal Hygiene	3.27	1.28
Feeding	3.55	1.33
Household Chores	2.85	1.28
Toileting	3.09	1.10
Identification of personal effects	2.73	1.35
Maintaining cleanliness	2.70	1.29
First Aid	1.97	1.16
Menstrual Hygiene	1.33	0.65
Routine	2.85	1.25
Overall Mean	2.7333	0.93

From table 3 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 were 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 may 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 may 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 deaf-blindness lack essential skills for survival in the community. This ultimately hinders their independence ability

Table 4: Extent of Acquisition of Orientation and Mobility Skills (n=33)

Skill	Mean	Standard Deviation
Maintaining appropriate posture and balance	3.61	1.22
Use mobility devices	2.73	1.46
Moving safely within the environment	3.64	1.11
Location of Objects within the environment	3.31	1.26
Location of place within the environment	3.42	1.15
use of body parts to explore the environment	3.48	1.18
Use of body parts to function the environment	3.30	1.21
Determining position in space and direction of movement	3.30	1.21
Carrying items from one place to another	3.42	1.30
Use of public amenities	2.82	1.33
Overall Mean	3.3091	0.94

From the table 4 it can be deduced that 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 included 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 while it is critical for them

Table 5: Extent of Acquisition of Communication Skills (n=33)

Skill	Mean	Standard Deviation
Expressive communication skills	2.85	1.00
Receptive communication skills	3.03	0.95
Establishing and sustaining attention	3.06	1.03

Use of appropriate augmentative communication and alternative communication	2.55	1.06
Names and function of objects	2.39	1.03
Communications with partners	2.64	1.14
Identifications of individuals	2.82	1.10
Communication in various domain	2.82	1.04
Use of alternative communication skills	2.88	1.11
Turn taking in communication	2.58	1.23
Overall Mean	2.7606	0.87

Table 5 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 of objects 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. This may result in challenges in carrying out basic meaningful conversations, interacting and using common objects within their environment.

It also puts them at risk of exclusion, access to information, social interaction and making informed decision making in life 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 6: Extent of Acquisition of Literacy Skills (n=33)

Skill	Mean	Standard
Deviation		
Pre-reading	1.79	0.78
Pre- writing skills	1.82	0.85
Identification and articulation of letters of the alphabet	1.73	0.94
Identification and articulation of numbers	1.67	0.85
Vocabulary Acquisition	1.64	0.89
Writing shopping list	1.39	0.79
Mathematical Operations	1.45	0.90
Measurement	1.61	0.97
Money	1.64	0.90
Entrepreneurial skills	1.58	1.03
Overall Mean	1.6303	0.74

Table 6 shows data on the extent of acquisition of literacy skill by learners with deafblindness. From table 9 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 was therefore 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 7: Extent of Acquisition of Vocational Skills (n=33)

Skill	Mean	Standard Deviation
Laundry	2.36	1.22
Beadwork	2.55	1.42
Cookery	1.73	1.01
Gardening	1.94	1.25
Animal Farming	2.06	1.17
Weaving and Basketry	1.79	1.05
Knitting	1.58	0.79
Woodwork	1.64	0.82
Cookery	1.64	0.96
Beauty therapy	1.61	0.86
Overall Mean	1.8879	0.91

Table 7 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=1.42) and laundry (Mean=2.36, SD=1.22). The skills that were yet to be acquired included beauty therapy (Mean= 1.61, SD=0.86).

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 and easily acquire the skill. Teaching the skill to the learners is equally challenging. Inability to carryout basic daily

chores such as laundry is a hindrance to transition to independent living.

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

Skill	Mean	Standard Deviation
Participation in game and sports	2.97	1.05
Participation in Music and dance	2.91	1.04
Building interpersonal relationships	2.79	1.21
Cooperation with others	2.88	1.24
Initiating Conversation	2.56	1.37
Participating and maintaining conversation with others	2.30	1.43
Problem solving	2.45	1.12
Self-management	2.48	1.25
Having preference and choices	2.64	1.34
Etiquette	2.39	1.06
Overall mean	2.6364	1.03

Table 8 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=1.43).

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. They 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.

Conclusion

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 to be minimal with vocational skills and literacy skills being the least acquired. Provision in terms of resources was found to be available but inadequate. There were limitations however 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:

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.

Organizing seminars and workshops for parents to empower them in supporting their deafblind children's education and eventual transition

Collaboration of schools with potential employers in securing opportunities and ensure smooth transition of learners with deafblindness

Provision of quality human and material resources by the government for effective skill acquisition by learners with deafblindness.

Strengthening policies related to early identification and transition of learners with deafblindness.

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. *"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%0THESIS%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, Terlektsi, 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-Children-and-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 deaf- blind. Monmouth, OR: National Consortium on Deaf- Blindness
- Manga, T., & Masuku, K.P. (2020). Challenges of teaching the deaf-blind 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/ilops_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.

Examining the Tactile Sign Language Used By And With The Deafblind In Ethiopia

Dr. Pawlos K. Abebe

Lecturer and Researcher, Addis Ababa University, Ethiopia

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.

Key words: deafblind, tactile sign language, deafblind communication, Ethiopia

Introduction:

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. Deafblind people use different methods of communication that suits their type of deafblindness. 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 places their hands-on top of a speaker's hands to receive the signs. The name "Tactile sign language" is used to refer to the method in this study.

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. Studies on various tactile sign languages including Tactile ASL (e.g. Petronio 1986; Collins & Petronio, 1998; Edwards, 2012, 2014b, 2014a, 2018; Haas et al., 1995, Collins, 2004), 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, et al., 2017), Tactile Japanese Sign Language (e.g. Bono et al.,

2018) , Tactile Australian Sign Language (Auslan) (Willoughby et al., 2014), Tactile Italian Sign language (LISt) (Checchetto, et al. ,2018) etc, all revealed that with proper adaptation Tactile Sign languages could be the way out of darkness for the deafblind.

These studies found the importance of contact and hand position in accomplishing turn-taking as well as identified various turn yielding signals such as returning the hands to rest position, decrease in signing speed and the indexing of addressee at the end of a turn, among others. Furthermore, the studies observed that to give feedback the deafblind utilize a variety of conventionalized taps, squeezes, grip cues, or 'haptics' which are unique to tactile signing. The studies also 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. There is, however, diverse opinion on whether Tactile Sign languages are natural, or 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, Checchetto, et.al. 2018; Deuce & Rose, 2019). 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. They, therefore, concluded that Tactile Sign languages are products of an effort aimed at making visual Sign languages accessible to the deafblind. An interesting observation made in a number of studies (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 study examined the Tactile Sign language used by and with the deafblind in Ethiopia in light of above findings.

Statement of the problem:

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. 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 used to enhance communication.

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:

- To identify the adaptations and modifications made to the visual EthSL to use it in a tactile form.

- To find out the features of the visual EthSL lost in the process of adaptations and modifications.
- To identify the strategies adopted to compensate for the loss of the grammatical features of the visual EthSL that can no longer be perceived.
- 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. Due to the fear of body contact imposed by COVID-19 restrictions throughout the duration of the study only two deafblind, a woman and a man, and two Deaf interpreters both males 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.

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.

The deafblind participants are regular church goers where most of their interactions happened. The two interpreters also worked with the deafblind in a church setting 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 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 of 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. However, no significant adaptations and modifications were observed in visual EthSL signed by the deafblind informants when they signed none tactually. The few modifications observed includes; allowing the deafblind to put their hands on the dominant hand and follow the signs and narrowing of the signing space. The other visible adaption 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 back of active hand held by the deafblind. During the interview session it was observed that 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 adaption 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 and how to adapt and modify in the visual EthSL. They thought the only adaption 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 thought the deafblind were smart enough to understand the random adaptations and modifications 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 kept 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) were 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 adaptations and modifications made on the communication

The communication observed was in most part ineffective. It was impacted negatively not by the modifications and adaptations made but by the lack of 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.

Discussions

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. The deafblind 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 L1St where they noted that whenever a L1S construction stops being perceivable in L1St a L1S 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. (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 & Petronio (1998) noted that signers in their study formed polar questions with the question mark sign. In agreement with this observation 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, et al.(1995) and 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 modifications 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. 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 are limited. Using more participants and making the assessment at multiple settings could have shed 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 the 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 were also not observed playing active roles 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 EthSL to the level of Tactual EthSL.

Recommendations

Providing effective services to the deafblind depends on the effectiveness of the communication method used. Therefore, the structure of the tactile sign language used in

Ethiopia needs to be studied and documented.

Efforts should be encouraged for the study of all tactile Sign languages in Africa in particular and the world at large in general.

Based on the research available a guideline on how to adapt and modify visual Sign languages into tactile Sign languages should be designed.

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.

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).

Appreciations

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
- Cecchetto, 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 & Eiríksdóttir, 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/>.

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 DeafBlind-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 -O. Östman, & J. Verschueren (Eds.), *Handbook of Pragmatics: 21st Annual Installment* (pp. 239-258). John Benjamins Publishing Company.

COVID-19: Implications For A Deafblind Adult In Ghana

Nana Opoku Acheampong

Lecturer, University of Education Winneba, Ghana

Gifty Nana Yaa Rockson

Lecturer, University of Education Winneba, Ghana

Cyril Mawuli Honu-Mensah

Lecturer, University of Education Winneba, Ghana

Background

Communication and socialisation are critical for comprehending and perceiving life circumstances, as well as getting insight into other people's experiences. For people who are deafblind, there is a severe mix of vision and hearing deficits, which makes communication, information access, and mobility difficult. Article 21 of the UNCRPD addresses access to information (United Nations, 2006) despite the fact that the person with disability had difficulty accessing information that was not always clear or understandable during COVID-19 pandemic. Besides, to interact with others, deafblind people require the constant presence of a caregiver who functions as an interpreter to function with other people. They may have to hire the services of an interpreter in some instances to aid their communication. In lieu of that, they frequently live a life of isolation and inaccessible information (Ebuenyi et al., 2020).

In a Policy brief '*A disability-inclusive response to COVID-19*' (May 2020) the United Nations stated that in any crisis-affected community, those with disabilities are among the most marginalised. They said that people with disabilities are less likely to have access to information, health care, education, and community participation. This implies that persons with disabilities will be more affected directly or indirectly during the COVID-19 pandemic. Statistically, about 6 percent of the global population representing an estimated 467 million people suffer combined hearing and vision impairments (IDA, 2020). This includes persons who acquired the condition due to ageing and are highly vulnerable to the COVID-19 virus. In a study report on the impact of COVID-19 pandemic on deaf adults, children and their families in Ghana, the authors reported that information about the pandemic had not been fully accessible to the deaf (Swanwick, et al., 2020).

The current study reports implications of COVID-19 on the communication and social life of an adult living with deafblindness. The adult, *Afia (not real name)*, is a post-lingual who comes from a family of three. She lives with her mother and brother (without an interpreter) in a city in Ghana. Her development as a child was normal without complications until she turned nine (9). At that age (Grade 3 in a Ghanaian basic school) she acquired adequate communicative skills in her native language (Twi) and English language before she became deafblind due to undiagnosed consecutive short illnesses. Presently, although she has no residual hearing or vision to benefit from the use of an amplification device, she is able to say some sentences to communicate her needs to a person who doesn't understand sign language. She is currently a final year student in the University of

Education, Winneba pursuing a bachelor's degree. She remains the only known adult living with deafblindness who has reached the level of education in West Africa. Her mother is a single parent who has no formal education but is able to communicate with Afia through gestures and idiosyncratic signs. *Afia's* brother has limited knowledge of tactile sign language and also communicates with Afia using gestures and writing on Afia's arms. Afia depends on her classmates and a paid interpreter for her communication needs to be met.

The COVID-19 pandemic has affected individuals, communities, countries and the world in different ways and persons with disabilities had their fair share of these effects. The United Nations advised that countries include persons with disabilities in COVID-19 response and recovery efforts because studies have shown that people with disabilities are among the most marginalised in any crisis-affected society (UN, 2020). In spite of this recommendation by the UN to promote the inclusive response to COVID-19 by member countries, persons with disabilities continue to cry for assistance to fully access information and adjust to life during the pandemic. The authors of a study on the impact of the COVID-19 pandemic on deaf adults, children, and their families in Ghana found that information about the pandemic was not fully accessible to the deaf, that adults deaf were unable to congregate in deaf space, that children were cut off from peer socialisation in schools, and that families of deaf children were deprived of trusted professional advice and support (Swanwick et al., 2020).

As a test of Ghana's commitment to the Convention of the Rights of Persons with Disabilities (CRPD) and Sustainable Development Goals 3, 4 and 10 during this pandemic, the current study seeks to understand the implication of COVID-19 on the communication and social life of a deafblind adult and the family. In order to meet the communication needs of the deafblind adult during the COVID-19 period, it was important to ensure that they had knowledge and understanding of information related to the pandemic and how to promote good health amidst the pandemic. In this sense, ascertaining the knowledge and understanding of COVID- 19 of the deafblind and their family is very crucial because it can result in an increase or decrease in the spread of the pandemic.

If COVID-19 is to be successfully controlled, a change in behaviour will be required, which is influenced by people's knowledge and attitudes, particularly in high-risk groups such as deafblind people who rely on body contact for communication. However, most COVID -19 studies around the world focus on a wider population of people with disabilities rather than deafblind people (Akalu et al., 2020; Senjam, 2020; Fitzgerald et al., 2020). Akalu et al., (2020) reported 33.9% which indicates a high prevalence of poor knowledge about COVID-19 among patients diagnosed with chronic diseases. And this is higher than previous research (Kebede et al., 2020; Zhong et al., 2020), which reported a low incidence of poor knowledge. The cause for the disparity could be related to a variation in context between research participants' socioeconomic level and health status. It could also be related to discrepancies in the method used to assess knowledge and the time of data collection.

Persons with deafblindness in Ghana, like in other countries, have fewer assistive technologies and limited knowledge of how to use computers and the internet space, making information access difficult and limiting their ability to understand health information and take health-promoting actions to combat COVID-19 (Paasche-orlow, et al.,

2016; Wolf et al., 2015). In their study, Estacio, Whittle, and Protheroe (2019) looked at socio-demographic factors linked to health literacy, internet access, and usage of health information. It was hypothesised that health information could improve patient understanding and practice. Health information has become more accessible online, and as such has implications for the differently abled persons including persons with deafblindness. Mantwill, Monestel-uma and Schulz (2015) are of the view that the main ways to ensure information access to the vulnerable or marginalised groups are through family, friends, health care workers and other service providers. However, in times of COVID-19, persons with deafblindness and family were to ensure minimal body contact, which affected the timely and efficient delivery of information with an accompanying low tendency of practising such information.

The social life of a deafblind individual is largely dependent on communicating with others who support them because they give information about other persons, events and activities. Those who provide support to these individuals can be family members, volunteers, and/or professional guide-communicators. In the global south context, the primary source of support for individuals with deafblindness is the family members and volunteers. Deafblind people can participate in a variety of activities with the help of family members to improve their social life and interaction (Hersh, 2013). During the COVID-19 pandemic, however, all individuals are to some extent deprived of this important social opportunity and people with deafblindness will feel this deprivation harder. People with deafblindness who utilise tactile communication and require assistance from support personnel to communicate with each other and obtain information are disadvantaged as a result of social distancing efforts to prevent the virus from spreading. This means there will be inaccurate information about the pandemic since they may have to depend on only one or few family members' understanding and perspective of the pandemic.

Williams et al., (2020) in their study reported that participants in the UK felt that information about the pandemic was not clearly communicated and there were 'mixed messages' about it. They also stated that there was a loss of money, structure and routine, and, more importantly, social interaction, all of which contributed to psychological and emotional distress which affected motivation, meaning, and self-worth. Although the pandemic brought some opportunities to some people globally, everyone experienced some form of loss as a consequence of the pandemic and its related global and national directives at reducing its spread.

Research context

This study was conducted in Ghana in Sub-Saharan Africa. Ghana is ranked as a low-middle income country (LMIC) and the prevalence of deafblindness is estimated to be 0.5% of the population (World Federation of the Deafblind, 2018). This is less than estimates in developed countries such as the US which has an estimated prevalence of 0.85%. Over the years, there has been increased advocacy and education for persons living with deafblindness. In Ghana, persons living with deafblindness are part of the Ghana National Association of the deaf (GNAD) which advocates to improve the inclusion of persons living with deafness (Swanwick et al., 2022; Opoku et al., 2020; Nyst 2010). However, levels of support for persons living with deafblindness is unknown in the Ghanaian context.

In Ghana, knowledge, infrastructure and support for people living with deafblindness is not available. Policies which are made specifically to support people with deafblindness are unavailable. For instance, there is no newborn hearing or vision screening and diagnostic programs currently. Therefore, children who have sensory impairment may be diagnosed very late. For instance, Swanwick et al., (2022) estimate that 20% of children may not be identified with a hearing loss until after they have turned age 5.

In the early years of their academic life, children with deafblindness are educated in the DeafBlind Unit which is attached to the Mampong Demonstration School for the Deaf. When they have reached Basic 4, they are educated in the same classrooms with their deaf peers and receive additional training in Tactile Sign Language and Braille from the DeafBlind Unit of the School until they graduate.

Methods and materials

Research design and participants

The intrinsic case study design was adopted for this study. In the *intrinsic* case study, the case is selected for its uniqueness which is of genuine interest to the researchers but not because it is representative of other cases (Crowe, et al., 2011). The case was chosen because the researchers considered it to merit investigation. In this study the adult with deafblindness was selected for the study because she is literate and could understand information about Covid-19 if given in accessible format. She is the only known adult in Ghana who had enrolled to pursue an academic programme in a University. Unlike the few other young pupils with deafblindness in a school for the deaf in Ghana, who are educated on COvid 19 issues by their teachers and are monitored and guided to ensure that they follow the Covid 19 protocols appropriately, she lives in the home community with her brother and mother. The participant's condition does not allow her to access information using residual vision or hearing. She is unable to use other forms of communication for the deafblind such as visual forms and tadoma (Hersh, 2013) and therefore predominantly communicates in tactile sign language.

Recruitment of participant

Afia was a student pursuing a Bachelor's degree in a public university in Ghana. She was contacted through the Resource Centre for Students with Special Needs located in the Department of Special Education in her school after Universities resumed academic work subsequent to the easing of restrictions on movement and re-opening of schools in Ghana. She is the only known adult who lives with deafblindness and had enrolled into a tertiary educational institution in Ghana. Although she is an adult, we also sought permission from her mother who was her caregiver.

Interview with Afia

The interview was carried out using tactile sign language. We videotaped the interview with permission from Afia and her mother and transcribed it into English, after which we generated a Braille transcription. Because we could only get this information through tactile

sign language, the interview had to be done face to face. We double checked the English transcripts and subsequently cross-checked the Braille transcripts with Afia, for accuracy (Temple and Young, 2004). English transcriptions were done independently by two of the researchers who are Sign Language Interpreters. The Braille transcription was also done independently by two researchers who were Brailleists. The pseudonym (*Afia*) was used in the transcription to protect the study participant's anonymity.

We used a multi-stage thematic technique to analyse the interview data (Braun and Clarke, 2006). After reviewing the interview transcript separately, we discussed the design of a code book, which we used to label out all of the transcript. Subsequently, we met as a team to decide which themes and sub-themes we would generate from the transcripts.

Data collection and analysis

The participant was also asked to thumb print to a consent form after detailed explanation both the whole research process and purpose was given. The participant was informed about the probable benefits and risk of participating in the study. Since the researchers are her lecturers and had a previous academic relationship with her, it was not difficult establishing rapport and scheduling interview dates. Data collection was conducted on June 8, 2021. The interview which was conducted in the home setting of the participant lasted for 80 minutes. The interview items were first braille and given to her to read through and familiarise herself with the issues. She asked for some clarification of some of the issues from the two researchers who could sign. After this clarification one of the researchers began signing the questions item by item for her responses. In order to gain accurate information from her, her permission was sought to videotape the interview session.

We used a multi-stage thematic technique to analyse the interview data (Braun and Clarke, 2006). After reviewing the interview transcript separately, we discussed the design of a code book, which we used to label out all of the transcript. Subsequently, we met as a team to decide which themes and sub-themes we would generate from the transcripts.

Trustworthiness

To ensure rigour in the study issues of trustworthiness were considered. In view of our knowledge that she has relatively limited vocabularies and finds it difficult to understand new vocabularies compared to her peers without the condition, we ensured that interview items were constructed in a language she will understand in order to avoid ambiguity and false information. According to Denzin and Lincoln, (2015) credibility is ensured by making the items free from ambiguity. This was possible by the input our colleagues made to the items and also a pre-test conducted on two high school students to test their understanding of the questions or items.

The transcript of the interview data was further braille and given to her to confirm if it is a true reflection of the ideas she wanted to communicate. This was a way to ensure dependability of the data collected. To also ensure confirmability, we have provided detailed description of the research processes. We have also tried to be unbiased to ensure that the research findings are grounded in the data and not influenced our values and knowledge.

Findings and Discussion

The main themes from the analysis were on experiences of an adult living with deafblindness relating to awareness and understanding of COVID-19, the communication strategies she used during the period and how the pandemic influenced socialisation.

Awareness and Understanding of COVID-19

The adult with deafblindness was aware of the existence of COVID-19. During the interview, the adult living with deafblindness described how she understood COVID-19:

I know that COVID-19 is a terrible disease that spreads so fast and it affects anybody at all. You can get infected through touch and not wearing a nose mask.

When it (COVID) first came, I met a lot of people and the explanation they gave me was confusing

Understanding was linked to how she got information about COVID-19 through workshops organised by GNAD and the information she had in accessible format. Awareness of the existence of the pandemic was linked with Disabled People's Organisations (DPOs) which provided education to persons with disability during the period. The participant indicated that Ghana National Association for the Deaf (GNAD) organised a sensitisation program for their members during COVID era.

I went to a workshop in Accra and we were given so much information on COVID. (.....) we were even given some materials in braille to come home and read more. This helped me.

Insights from the interview reveal the need for access to information and how this influences the understanding of COVID-19 in the adult living with deafblindness.

Access to information

In this study, the awareness of the pandemic and the understanding of how the disease is transmitted is influenced by access to information. We are not able to state whether the information the adult living with deafblindness had was adequate because the workshop which was organised by the GNAD occurred 3 months after the pandemic had started and restrictions were imposed. In Ghana, there were bi-weekly updates about the restrictions and measures the Government of Ghana has instituted to curb the spread of the disease. There were also weekly meetings with the Ministries of Information and Health. However, these regular updates were telecast on only the electronic media and print media. Details of the updates were not available in braille for the adult living with deafblindness to access during the period.

In this study, the awareness of the pandemic and the understanding of how the disease is transmitted is influenced by access to information. We are not able to state whether the information the adult living with deafblindness had was adequate because the workshop which was organised by the GNAD occurred 3 months after the pandemic had started and restrictions were imposed. In Ghana, there were bi-weekly updates about the restrictions and measures the Government of Ghana has instituted to curb the spread of the disease. There were also weekly meetings with the Ministries of Information and Health. However, these regular updates were telecast on only the electronic media and print media. Details of the updates were not available in braille for the adult living with deafblindness to access during the period.

Fear

Also, insights from the interview revealed that knowledge and level of understanding of COVID 19 issues made the adult living with deafblindness develop fear. She feared she could contract the virus since she cannot identify an infected person who may come close to her.

If a person I meet has COVID 19 I will not know so I was terrified and so I made sure I follow all the protocols, wear my mask and use the sanitizer more frequently

Tactile sign language provisions were not made for the ministerial updates and announcements. Although there were sign language interpreters available at every meeting, for the adult living with deafblindness, she needed an interpreter to be present with her to have access to information. The absence of an interpreter during the period caused her to be scared and edgy. Besides there were various videos explaining the pandemic but again, the absence of an interpreter and the scare of the pandemic led to apprehension in the adult living with deafblindness.

Given that access to information continues to be a major barrier for deafblind people (Wittich et al., 2016), it was no surprise that GNAD was needed to organise a workshop for deafblind people to provide information about COVID-19. As researchers, we are concerned about deafblind people gaining access to sensitive information that will aid in the better understanding and awareness of diseases and ailments. According to Wittich et al. (2020), there was an immediate research and knowledge translation response within and about the culturally deaf, audiotically deaf, and blind communities, with a focus on uni-sensory impairment priorities and COVID-19-specific adaptations but not for the deafblind people. Besides, these adaptations did not apply to Low-middle Income countries like Ghana. With regards to the finding from this study, the participant did not benefit from an immediate response for a deafblind program but a program organised to sensitise the deaf community. The good thing is that, GNAD provided the deafblind with a braille version of materials on COVID-19.

Communication

Communication with relatives and other people was a challenge during COVID -19 pandemic was a major challenge for the participant.

During that time my brother came and stayed with us(at home), but we were not communicating (because he cannot sign to me)

Physical distancing was one way of minimising the spread of COVID-19. This affects the use of tactile sign language.

(...)because everyone knew that COVID could spread through touch, people avoided getting close to me to avoid communicating with me through touch.

I could not meet my friends and then I had a challenge getting information because I depend solely on my friends to explain what happens in the community to me

Our findings from the study indicate that the participant had challenges with communication during COVID-19. Undoubtedly, the deafblind communication is mainly through touch and for that matter, physical distancing as a protocol poses a communication challenge for individuals with deafblindness. This was reflected in the statement above. It is important to note that the participant in this study had serious challenges as a result of COVID protocols that mentions physical distancing. This agrees with Wittich et al (2021) who stated in their study that deafblind participants mentioned that an added challenge was the combination of physical distancing and wearing of a nose mask. We discovered that because she could not access information through the media or government channels, the deafblind participant became even more reliant on her family members. The participant becomes heavily dependent on family to supply health information and life-sustaining support. This was generally the case during lockdowns, when people were cut off from social services, schools, and workplaces

It is uncommon for family members to be fluent in sign language or to know how to successfully support the deafblind in order to protect her from the pandemic within that short period. In addition, the participant reveals that the mother is unable to read and write. This makes it a concern to the researcher how the mother is able to confirm information received in her local language from some government source that usually communicates in English Language. There is also a concern as to how the mother is able to communicate this relatively new information to the participant. This notwithstanding the participant revealed how she relies on the mother for information on the pandemic. She had this to say in this regard:

My mother was communicating with me about the pandemic using gestures and sometimes she tries to write on my body.

I think I needed an interpreter during the initial stages of the pandemic when we were all learning about it. My mother couldn't communicate with me well.

Another important theme that emerged from the data was socialisation. As much as socialisation was challenged through the various restrictions imposed by countries and the need to follow the preventive protocols, there were other avenues people related and socialised. However, for the adult with deafblindness, there was relatively no opportunity to meet her socialisation needs during the time of increasing infection of the virus.

I was able to use Facebook and WhatsApp to socialise with friends and family because a friend always comes around to read messages for me. But during the COVID-19 period the friend was not able to come to me so I also could not relate to others on the social media although that was the main means of socialisation at that time.

She further intimated this by saying that:

It was boring during that period because there were no friends around.

This issue of socialisation is closely related to communication in the sense that one needs to communicate to be able to socialise. This issue of socialisation for deafblind people is closely linked to a study conducted by Abdelmagid, Fasla, & Elhadeif, (2021) who identifies the problem of socialisation for the deafblind and invented a “bracelet or wrist watch-like” device that is intended to help the deafblind to effectively socialise and communicate. The device invented allows the deafblind to communicate independently and spontaneously,

Conclusion

The experiences of an adult living with deafblindness bring to light the importance of understanding the impact of accessible information and interactions between people living with deafblindness and their caregivers and families. The adult living with deafblindness is dealing with new experiences connected to adhering to COVID-19 safety protocols. A person's experiences as a deafblind person are influenced by a number of circumstances, including their capacity to communicate effectively in the absence of an interpreter in LMICs like Ghana.

In order to improve access to information for people who are deaf blind, a better awareness of the personal obstacles and communication challenges would be necessary. Investments in DPOs like GNAD and GBU could offer members with information in easily accessible formats. In order to facilitate good communication, further training for caretakers of people who are deafblind is also crucial. The COVID-19 experience provides contextual knowledge for deafblind people's life, fostering increased social awareness, accountability, and prospects for change toward a more inclusive society. Further research is required to understand the social life and communication needs of the deafblind adult.

REFERENCES

- Abdelmagid, F., Fasla, H., & Elhadeif, M. (2021, August). *Jusoor: A Wearable Communication Device*
- Akalu, Y., Ayelign, B., & Molla, M. D. (2020). *Knowledge, Attitude and Practice Towards COVID-19 Among Chronic Disease Patients at Addis Zemen Hospital, Northwest Ethiopia*. Dovepress Vol.13 Pg.1949—1960. Retrieved online at <https://www.dovepress.com/knowledge-attitude-and-practice-towards-covid-19-among-chronic-disease-peer-reviewed-fulltext-article-IDR> 2/8

- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology*, 11(1), 1-9.
- Denzin, N. K., & Lincoln, Y. S (Eds.) (2015). *The Sage handbook of qualitative research*. Thousand Oaks, CA: Sage Publication.
- Ebuenyi, I. D., Smith, E. M., Holloway, C., Jensen, R., D'Arino, L., & MacLachlan, M. (2020). COVID-19 as social disability: the opportunity of social empathy for empowerment. *BMJ Global Health*, 5(8), e003039. <https://doi.org/10.1136/bmjgh-2020-003039>
- Estacio, E.V., Whittle, R. & Protheroe, J. (2019). Examining socio-demographic factors associated with health literacy, access and use of internet to seek health information. *Journal of Health Psychology*, 24 (12):1668–1675. Doi: 10.1177/1359105317695429
- Fitzgerald, H., Stride, A., & Drury, S. (2020). COVID-19, lockdown and (disability) sport. *Managing Sport and Leisure*, 1-8. <https://doi.org/10.1080/23750472.2020.1776950>
- For the Deaf-Blind: An Ideation-Themed Capstone Project. In *The 7th Annual International Conference on Arab Women in Computing in Conjunction with the 2nd Forum of Women in Research* (pp. 1-5).
- Hersh, M. (2013). Deafblind people, communication, independence, and isolation. *Journal of deaf studies and deaf education*, 18(4), 446-463. <https://doi.org/10.1093/deafed/ent022>
- Kebede, Y., Yitayih, Y., Birhanu, Z. & Mekonen, S. (2020). Knowledge, perceptions and preventive practices towards COVID-19 early in the outbreak among Jimma university medical center visitors, Southwest Ethiopia. *PLoS One*, 77 (5):1–15. doi: 10.1371/journal.pone.0233744
- Mantwill, S., Monestel-uma, S. & Schulz, P. J. (2015). The relationship between health literacy and health disparities: a systematic review. *PLoS One*, 10(12):1–22. doi: 10.1371/journal.pone.0145455
- McGrath, C. Palmgren, P. J & Liljedahl, M (2019) Twelve tips for conducting qualitative research interviews, *Medical Teacher*, 41:9, 1002-1006. <https://doi.org/10.1080/0142159X.2018.1497149>
- Paasche-orlow, M., Hironaka, L. K. & Paasche-orlow, M. K. (2016). The implications of health literacy on patient – provider communication. *Archives of Disease in Childhood*, 93:428–432. <https://doi.org/10.1136/adc.2007.131516>
- Senjam, S. S. (2020). Impact of COVID-19 pandemic on people living with visual disability. *Indian journal of ophthalmology*, 68(7), 1367.

- Swanwick, R., Oppong, A. M., Offei, Y. N., Fobi, D., Appau, O., Fobi, J., & Frempomaa Mantey, F. (2020). The impact of the COVID-19 pandemic on deaf adults, children and their families in Ghana. *Journal of the British Academy*, 8, 141-165. <https://doi.org/10.5871/jba/008.141>
- United Nations (2006). *Convention on the rights of persons with disabilities (CRPD)*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- United Nations (2020). *A Disability-inclusive Response to COVID-19*. Retrieve from <https://www.un.org/en/coronavirus/disability-inclusion>
- Williams, S. N., Armitage, C. J., Tampe, T., & Dienes, K. (2020). Public perceptions and experiences of social distancing and social isolation during the COVID-19 pandemic: A UK-based focus group study. *BMJ open*, 10(7), e039334. <https://doi.org/10.1136/bmjopen-2020-039334>
- Wittich, W., Jarry, J., Groulx, G., Southall, K., & Gagné, J. P. (2016). Rehabilitation and research priorities in deafblindness for the next decade. *Journal of Visual Impairment & Blindness*, 110(4), 219-231.
- Wittich, W., Nicholas, J., & Damen, S. (2021). Living with deafblindness during COVID-19: An international webinar to facilitate global knowledge translation. *British Journal of Visual Impairment*, 02646196211002887.
- Wolf, M. S., Gazmararian, J. A. & Baker, D. W. (2015). Health literacy and functional health status among older adults. *Arch Intern Med*. Vol; 165(17):1946–1951. <https://doi.org/10.1001/archinte.165.17.1946>
- World Federation of the Deafblind, WFDB (2018). *Global Report 2018: Persons with Deafblindness and Inequality*. <https://wfdb.eu/wfdb-report-2018/deafblindness-and-inequality/>
- Zhong, B., Luo, W., Li, H. et al. (2020). Knowledge, attitudes, and practices towards COVID-19 among Chinese residents during the rapid rise period of the COVID-19 outbreak: a quick online cross-sectional survey. *International Journal of Biological Sciences*, 16(10):1745–1752. <https://doi.org/10.7150/ijbs.45221>

Natural Communication Abilities among Children with Congenital Deafblindness in Multi-Linguistic Communities of Zambia

Brighton Kumatongo
Lecturer, Kitwe College Of Education, Zambia

Douglas Gawani Phiri
Lecturer, Zambia Institute of Special Education, Zambia

Abstract

Children with Deafblindness among 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.

Keywords: Children, Congenital Deafblindness, Parents, Natural Communication

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 conversations 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 effectively 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 sensational 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 can 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 communication sign to express discomfort, frustration and attention. In one of the videos that lasted for 1 minute 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 where the object which she wanted was kept. Sometimes she could tap your body and in some cases she would vocalise 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 direction 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, folk 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.

DISCUSSION

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, clapping 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 the that 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 using 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* concur 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

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.

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:10.1177/026461961038749
- 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.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.

Knoors, 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/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.

Towards Equitable Social Protection for Persons with Deafblindness In Uganda. A Case Study of The State's COVID-19 Interventions

Dr. Aniyamuzaala James Rwampigi
Researcher, University College Dublin, Ireland

Abstract:

Persons with Deafblindness were among the Person with disabilities most affected by poverty (WHO & World Bank, 2011). They faced multiple barriers ranging from lack of support services and inaccessible information and communication. These barriers result into their limited participation in education, employment and others (WFDB, 2018). The Convention on Rights of persons with Disabilities (UN,2006; Article 28) provides for the right to adequate Standard of living and social protection for Persons with Deafblindness. The 2015 Uganda National social protection Policy does not recognise Persons with Deafblindness. The Social Assistance Grants for empowerment (SAGE) targeted only persons who are above 80 years and above. SAGE did not prioritise Persons with Deafblindness. The 80% of the research participants with Deafblindness did not get COVID relief assistance from government of Uganda. The government should establish a national social protection programme for Persons with Deafblindness to compensate their related costs and maintain their wellbeing.

Introduction:

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. Furthermore, Persons with Deafblindness face multiple barriers ranging from lack of support services, social protection, inaccessible information and communication and others. This resulted into their limited participation in education, employment and community activities.

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. 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. The Social protection interventions in form of direct cash transfer, food assistance, social insurance and others were among the COVID-19 responses according to International Disability Alliance (2019; *Gentilini et al, 2020*). The research report revealed that Persons with disabilities including Person with Deafblindness were excluded in the COVID-19 responses (IDA, 2021). Uganda ratified the United Nations Convention on Rights of Persons with Disabilities in 2010. Article 28 of the UNCRPD requires State in Uganda to Provide adequate standard of living and Social Protection to Persons with Deafblindness and other categories of Persons with Disabilities to overcome barriers and cover the extra cost of disability. The 1995 Uganda’s Constitution does not recognise the right to social protection directly.

However, article 32 of the 1995 Constitutions requires the Ugandan state to take measures including development of laws and programmes that equalise the opportunities for Persons with Deafblindness and other categories of Persons Disabilities. 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, it does not recognise the right to Social Protection for Persons with Deafblindness in Uganda. The 2015 Uganda National social protection Policy does not recognise Persons with Deafblindness. The National social security fund (NSSF) and Uganda pension funds provided social security to workers.

Based on the above background, this research paper examined how the COVID-19 Social protection interventions covered fully and equitably the needs of Persons with Deafblindness in Uganda. The main research question was how did the government of Uganda’s COVID-19 social protection interventions cover fully and equitably the needs of the Persons with Deafblindness in Uganda? The research paper tested the research theory that stated that all the government Social protection interventions and programmes including those on COVID-19 social protection interventions covered the responded needs of all 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 Social Protection provided by Government of Uganda between 2020 and 2021.

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 quantitative 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 COVID-19 Social protection interventions cover the needs of 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 Social Protection interventions? Which Social protection interventions were used by government of Uganda to cover the needs of Persons with Deafblindness? The equity was measured by the social protection coverage of all Persons with Deafblindness and their needs.

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.

The findings:

The results of the research study were as follow below:

1. The representative of the National Council for Persons with Disabilities stated that “Government does not have official national statistics for Persons with Deafblindness. Uganda Bureau of Statistics used the Washington group set of questions on Disability statistics that do not facilitate collection of specific data for Persons with Deafblindness directly. However, the 2020 Persons with Disabilities Act recognizes Persons with Deafblindness as one of the groups of Persons with Disabilities in Uganda and requires the State to collect specific population data on Persons with Deafblindness in Uganda”. The representative of the National Association of the Deafblind Persons in Uganda (NADBU) stated that “There is no official government statistics on Persons with Deafblindness in Uganda. NADBU have approximately 500 members and we continue to register members as we find them in communities”. This confirmed the challenge of data desert of Persons with Disabilities in Uganda.
2. The representative of the National Council for Persons with Disabilities stated that “the government provided COVID-19 cash assistance and distributed food to vulnerable households during COVID-19 period between 2020 and 2021. Government did not have specific interventions for Persons with Deafblindness and other persons with Disabilities”. There were considered to be part of the general public reached out by government programmes”. This data confirmed that government did not priorities Persons with Deafblindness and their caretakers in the social protection Interventions.
3. One of the Persons with Deafblindness stated that “government provided money and food to some people, but I did not benefit from the cash and food provided by the government”. The representatives of NADBU stated that “some of our members and their care takers requested support in form of food and cash assistance from us. Others wanted to know how to get the government’s cash and food assistance”. The 80% of the research participants interviewed did not benefit from the COVID -19 cash and food assistance. This data confirmed the government COVID-19 social

protection assistance excluded Persons with Deafblindness in Uganda. The 20% of the research participants interviewed received food assistance distributed by office of Prime minister. However, this part of the households that received the government food assistance. Government did not specific interventions targeting Persons with Disabilities Including Persons with Deafblindness.

4. The representative of the national Council for Persons with Disabilities stated that “The Social Assistance Grant for empowerment(SAGE) provides a monthly cash assistance to Older Persons above 80years currently. It does not target Persons with deafblindness and other Persons with Disabilities”. This empirical data validated the early findings based on the secondary data and confirmed that the existing social protection programmes in Uganda did not prioritize Persons with Deafblindness and did not cover their needs during the COVID-19 Pandemic.
5. One of the Care takers stated that “I spend all day taking care of my son because he needs my support to live. I am not able to look for paid work and government does not provide support to my son or me. We live by Mercy of God” . This data confirmed that government of Uganda does not have a care policy that compensates the work provided by care takers to Persons with Deafblindness and others in need of care takers.

The Recommendations:

The research study makes the recommendations below based on results above.

1. The Government should review the existing national social protection policy to prioritize Persons with Deafblindness as one of the groups of persons with disabilities in need of social assistance and cash assistance.
2. The government of Uganda should develop a social protection and welfare legislations or Acts that provides for funding and support to Persons with Deafblindness and other categories pf Persons with Disabilities.
3. The Government of Uganda should develop a funding policy and programme for Caretakers to compensate their labour time.
4. The National Association of Deafblind Persons in Uganda should change from being only an advocacy organization to both social care and advocacy organization.

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 32
4. Uganda, 2015, National Policy on Social Protection
5. IDRC-OCAD University, 2018, what is inclusive Design, <https://idrc.ocadu.ca/>
6. Uganda Bureau of Statistics (UBOS), 2014, Uganda Population and Housing Census report
7. Uganda Bureau of Statistics (UBOS), 2017, Uganda Functional Difficulties report
8. Sense International, 2021, Population of the persons with Deafblindness in Uganda.
9. International Disability Alliance (IDA), 2021, The Survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic
10. Leeds-Hurwitz, W. (2009). Social Construction of Reality. In S. Little John, & K. Foss (Eds.), *Encyclopaedia of Communication Theory* (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>
11. Fairclough, N., 1995, *Critical discourse analysis The critical study of language* London Longman, 1995 Pp 132
12. Fairclough, N., 2005, *Peripheral Vision: Discourse Analysis in Organisation Studies: The Case for Critical Realism*
13. Robert Yin, 2018, *Case study Research*.
14. Gentilini, Ugo; Almenfi, Mohamed; Orton, Ian; Dale, Pamela. 2020. *Social Protection and Jobs Responses to COVID-19: A Real-Time Review of Country Measures*. World Bank, Washington, DC. © World Bank. <https://openknowledge.worldbank.org/handle/10986/33635> License: CC BY 3.0 IGO.

Management Strategies for Children with Deafblindness in Special Education Schools in Lusaka, Zambia

Racheal Chomba
Teacher, Munali Girls Secondary School, Zambia

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

- 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 deafblindness.

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 & Jerkins, 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).

An individual 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 take 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 be 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

3.0 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:

- 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 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 daily living so you

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

A male head teacher 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-blindness 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 where 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 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

4.0 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 to 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 child’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 understand 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

5.0 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 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 businesses 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:

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

Teacher training programs in colleges and universities to be revised to meet the current needs of learners with deaf-blindness.

Distribution of the required specialized materials and assistive devices in schools to foster teaching and learning of children with deaf-blindness.

The Ministry of General Education to liaison with the Ministry of Health in providing education to parents through support groups upon diagnosis.

Sensitizing schools, regular teachers and administrators against discrimination of learners with deaf-blindness

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

- The role and importance of parental involvement in the education of deaf-blind children
- Intervention strategies for children with deaf-blindness
- 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 MM. JB, 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. *DbI 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 Paulines Publication Africa
- 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.

Five Years Of Experience Delivering High Quality Teacher Training Online Education. Experiences and Tips To Share

Karina Elizabeth Medina

Southern Cone and Andean Regional Representative, Perkins International, Perkins School for the Blind

In 2016 Perkins School for the Blind launched a new global teacher training initiative to address the shortage of trained teachers who could provide appropriate educational services to children and youth with vision loss, additional disabilities including those with deaf blindness. The courses called 'Education of Learners with Multiple Disabilities and Sensory Loss' were divided in three levels – Foundations, Advanced, and Program Development. For Perkins with 100 years of international teacher training expertise, this was the first-ever international competency course for teachers working with this specific population. In Latin America and the Caribbean, we delivered these courses mostly online in conjunction with higher education entities and secretaries of education. To the present day we have delivered 25 online training courses, 120 hours long each course, to teachers, professionals and adults who are deafblind from 14 countries.

The educators participating so far have been mostly teachers from regular education, special education teachers, physical education teachers, speech and language therapists, psychologists, and educational technicians, supervisors, and ministry of education officials. The PI Academy Foundations (Course 1) Advance Course (Course 2) and Developing Quality Programs (Course 3), consist of 4 modules each on the topics of Learners with Multiple Disabilities and Sensory Impairments, Communication, Assessment, Curriculum, Expanded core curriculum, teamwork.

The course has synchronous and asynchronous classes which means that students log on to a course on their own time but also, they have class by zoom once of week.

Participants are graded according to their participation, the completion of assignments and a portfolio, an action plan and one post-test for each module, according to the dynamics of each course. When passing the course they receive a PI Academy certificate and the University with whom Perkins International has an agreement in each country (Brazil, Argentina y México) or with the Secretary or Ministry of Education.

In these 5 years the resources and means used to develop the courses and the virtual classes have been evolving, improving and at the same time proposing new challenges for teachers and students. To guarantee the full participation of all participants, activities were proposed using applications such as WhatsApp, Mentimeter, interactive whiteboards, group work through TikTok, shared elaboration documents, synchronous classes by Zoom or Meet, accessible PDF, PPT with subtitles, among others.

Online education is a teaching modality with its own characteristics that is developed in a particular space generating unique teaching and learning processes. From the experience in the last years, some adjustments were made into the courses. With respect to the processes, adjustments were made in the administration of the learning materials, in the distribution of the times and fulfillment of the activities, the amount of activities, the types

of activities, the incorporation of tasks that facilitated the comprehension and learning. It is very important to incorporate spaces for group meetings. Teachers' support to the participants are also strengthened in different ways, both in the orientation of the topics that were developed, as well as in the feedback and advice in the activities developed by participants.

The course in general is enriched with the incorporation of theoretical material that allows the articulation between the different modules, as well as contextualizing the training understanding the reality in each country. In relation to the benefits of the online modality of training, we can mention that educators from all corners of the country and region can take a high quality course, not only those who live close to big cities; the community of learners and tutors benefit from the differences in cultures and experiences from their region or country of origin, it is an option that responds to the needs and preference of many students, it is flexible because it allows a combination of modalities.

Conclusion

Online training is a real option that has taken an important role especially in the last two year (2020-2021) because of the pandemic. Many people managed to continue their studies, thanks to the resources to provide synchronous and asynchronous classes. The principles of good teacher training apply equally for in-person and online, what changes is the form of teaching and learning and in consequence the culture.

For Perkins International from Perkins School for the Blind who has been training teachers for decades in different parts of the world, being able to make a proposal that allows online training also means giving greater opportunities to children and young adults with multiple disabilities and their families to receive a quality education. The reason is that their educators are having access to high quality training, no matter where they are located in the wide world.

The objective of this presentation is to share our experience in successful practices and some of the challenges in the implementation of a course in online format including accessible technological resources that guarantee the participation of all people and the development of quality learning.

References

- Czubaj F. (2012) Cada vez más, las universidades migran hacia el ciberespacio – Artículo -LA NACION <https://www.lanacion.com.ar/1488989-cada-vez-mas-las-universidades-migran-hacia-el-ciberespacio>
- Diaz, A. ; Klotzman P., Rodriguez-Gil, G. (2019) **Developing an Engaging Online Experience for Participants of Perkins International Academy Courses in Latin American and the Caribbean**. DBI Review No. 62, June 2019, Pages 66-69.
- Henry, J. & Meadows, J. (2018) Un curso virtual totalmente fascinante: nueve principios para la excelencia en la enseñanza en línea. Canadian Journal of Learning and

Technology Vol 44, No 3 En español disponible en: <http://www.pent.org.ar/centro-de-recursos/un-curso-virtual-totalmente-fascinante-nueve-principios-para-excelencia-ensenanza>

Kelly, H. F., Ponton, M. K., & Rovai, A. P. (2007). A comparison of student evaluations of teaching between online and face-to-face courses. *The Internet and Higher Education*, 10(2), 89–101. doi:10.1016/j.iheduc.2007.02.001

Pardo Iranzo, V. (2014) La docencia online: ventajas, inconvenientes y forma de organizarla. *Revista Boliviana de Derecho*, N° 18, 628. Recuperado de: <http://www.scielo.org.bo/pdf/rbd/n18/n18a37.pdf>

UPI Español y La Nación (2012) Crece en Argentina la Educación a distancia- Artículo- Universidad Argentina

DAY 2: FRIDAY 13TH MAY 2022

KEYNOTE SPEECH - RIGHT TO EDUCATION AND TRAINING FOR PERSONS WHO ARE DEAFBLIND IN AFRICA - THE ROLE OF INSTITUTIONS OF HIGHER LEARNING AND RESEARCH

Professor Olusola Bandele Oyewole
Secretary-General Association of African Universities, Ghana

On behalf of the Association of African Universities Accra Ghana, permit me to first of all congratulate DeafBlind International on the occasion of this first conference on deafblindness that is being held in Nairobi, Kenya from 12-14th of May 2022. I will be speaking on this occasion on what I call the right to education and training for persons who are deafblind in Africa.

Ladies and Gentlemen,

Education is a critical element for development and knowledge. Education is an avenue through which countries in Africa can empower their people to contribute to their development. Education, especially Higher Education has been known to be important for the economic, political, and social development of the people of a place. It is not just important for the nation. Education has also been found to enhance the quality of life of an individual, making the economic potential of that person better and also impact the person to contribute to the development of the community. Ladies and Gentlemen, on this occasion or the first Deaf Blind Conference on Deaf Blindness, I want to ask ourselves, who has the right to education? And I would submit that the right to education is a fundamental human right of every individual irrespective of their race, gender, nationality, ethnic or social origin, religion or political preference, age or disability.

Ladies and Gentlemen,

Those who are disabled in one way or another can contribute to national development and have the right to education. I want it to be made clear that education is not a privilege, it's a human right. Education as a human right means, the right to education, which is legally guaranteed for all without any discrimination. Education as a right and not a privilege also means that the state has an obligation to protect, respect and fulfil the rights of the citizens to education.

Ladies and Gentlemen,

Education is a basic human right for all and is important for everyone to make the most of their lives. Other human rights apart from education include right to freedom, right to be free from slavery or torture and freer trials. Having an education helps people to access all the other human rights. Therefore, Ladies and Gentlemen, I believe that irrespective of the state of an individual, we should not deny them of their rights to education. This is exactly what is behind the African Union Agenda 2063. The agenda that says the need for a

prosperous Africa, based on inclusive growth and sustainable development are well-educated citizens with skills that can revolutionize our development.

Ladies and Gentlemen,

When we talk of the rights to education, what of the deafblind in our society? Do they have rights to education? Probably we need to seize this opportunity to educate ourselves. There are people who are blind. I am not talking about those ones now because we have provisions for their education. There are people who are deaf. I am also not talking about those ones because we have technologies and other facilities to cater for the education of these ones. But do you know that there are people within our society who are deaf and blind? a unique word. Deafblindness is a rare condition in which an individual has a combined hearing and vision loss, thus limiting access to both auditory and visual information. You may be wondering what may have caused such a situation in their life. There are many causes of deafblindness. Those that are present or occur around the time when the child is born include prematurity in delivery, childbirth complications, and numerous congenital syndromes, many of which are quite rare. Beyond this, people can become deafblind even in childhood or during adulthood, due to causes such as meningitis, brain injury, or other inherited conditions.

Ladies and Gentlemen,

It is for the deafblind that I'm speaking today. The deafblind have some barriers that they face in life. One is movement challenges. While you will decide to move about; while you can hear, can move about freely, those who cannot see and who cannot hear are limited in the extent to which they can move. They also have communication challenges; how do they speak to you? How do they hear from you? This is a big challenge in their lives.

Ladies and Gentlemen,

We need to be concerned about the barriers that confront the deafblind. They are unable to partake in leisure and social activities like you and me. Much more than others, they do not have access to education except when we do something to help them. The deafblind need your understanding. They need my understanding to help them also survive in our society, they have the right to life. We need to be their advocates. Since they are deaf, and they are blind, they cannot speak for themselves, and they depend on you and me to be their advocates.

Ladies and Gentlemen,

We need to be conscious of their needs and see what we can do to provide for the needs of the deafblind among us. What are the needs of the deafblind? They cannot be accommodated in special education programmes like the one we provide for the solely deaf or the solely blind. Their own situation appears to be different from these two disabilities that I have talked about. Impairments of sight and hearing at the same time require some thoughtful and unique educational approaches in order to ensure that children with this type of disability have the opportunity to reach their full potential in life.

The disability of deafblindness presents unique challenges to families, teachers and caregivers who must make sure that the person who is deafblind has access to the world beyond the limited reach of these individuals.

Ladies and Gentlemen,

The people in the environment of the children or adults who are deafblind must also help them. They need to help them with their movements, they need to find a way of communicating with them. What I am saying today is that the deafblind are in a unique world. The world of the deafblind extends only as far as they can touch and feel with their fingerprints. For those individuals, for those young people, for those babies, for those children with that condition, what can we do to educate them? This is the focus of this first conference of the deafblind in Africa. This is the first time that we will be talking about their needs in Africa. I know that other continents like the United States of America, like Europe, have special provisions for them. Those of us in Africa, what can we do to educate the deafblind? And that's why I want to share with us some of their unique educational and services' needs. Number one: They need lifelong support that helps them to function like other human beings. They need a unique educational system which cannot be catered for by the educational system that is available everywhere. We need to create for them a unique social environment in which they will not be discriminated against.

Ladies and Gentlemen,

These individuals are only deafblind; they have skills and potentials that can contribute to our society. Can we help them? They need security, they need to be protected. They need safety. What can our society do to help the deafblind? This is a call of this time. Can we provide them with the technological support that can help overcome the challenges of deafness and blindness? Have you ever considered that the deafblind go through some stress and frustration which are not expressed by other children? I need to see this today, that the condition of deaf and blind children attracts some other disabilities such as disruption in their ability to sleep or disruption in their sleeping patterns, feeding difficulties, and some other health problems. For this unique type of people in our society, what can we do to make life better? We do need to know that there are some major challenges that these individuals face: communication challenges, social challenges, and lack of support in their environment to educate them.

Education is very important for all, and we must provide education for the deafblind. The limited sensory channels available for learning necessitate that we develop some highly individualized programmes for each child that is deafblind. What strategies shall we as African adopt to provide support for the deafblind among us and I'm going to provide some strategies.

#1 It's important for children with deaf blindness to be identified early in life when the brain is more sensitive to add to learning and begin receiving attention. In our society it takes such a long time to know the situation of deafblindness. It is very important that we recognise these deficiencies, these challenges are realized early. #2 It is also critical that families and educators who will take care of the deafblind have access to appropriate

training that can help them to cater for the deafblind.

Ladies and Gentlemen,

In Africa, we need to build such capacities in our teachers so that they can help to take care of these unique people among us. We need to provide some unique technological or learning aids to help the deafblind to also access education in their lifetime. We need to create a conducive social environment for their growth and their development. Ladies and Gentlemen, I believe that this conference that is being held in Nairobi, Kenya will help the whole of Africa. We've started late, but it is not too late to begin to take care of these deafblind. I believe that higher education institutions which the Association of Africa universities represent, have some roles to play. What are the roles that higher education institutions can play in helping the deafblind in our continent? Number one, we need more research, let our researchers carry out more research on what they can do to help the Deafblind in our midst. We need technological interventions. I believe that we can help them to access some facilities or education through technology.

Higher educational systems need to train the trainers and those who support this deafblind. For sure you will not expect that they will use the same curricular like those who are not deaf and those who are not blind. So, we need to provide unique curricula to meet the individual needs of the deafblind. Let us give them opportunities for higher education. They should not just be allowed to remain at the primary level. They also have the potential to go beyond the primary school level. Let us educate them as we educate others in our communities. I want to congratulate the organizers of this first deafblind international conference in Africa that is being held in Nairobi, Kenya. This conference that is being organized by the DeafBlind International Africa, is a regional platform for connecting individuals who are deafblind, their families, professionals, researchers, developers, service organizations, libraries, universities, national and international agencies, and other public and private partners in the field of deaf blindness.

Permit me to share with you the objectives of this conference that is being held.

#1: To bring together and connect individuals who are deafblind, their families, professionals, researchers, service providers, government representatives, and other public and private sectors at the national and the international levels to discuss issues related to deafblindness.

#2 This conference is being held to contribute to the improvement of services for persons with deafblindness in Africa through sharing of research, best practices, and expertise in the care of people with deafblindness.

#3 And I believe that this conference will help to raise awareness among governments and other public and private institutions in Africa, and around the world on deafblindness as a distinct disability, on the need to promote the development of appropriate services through policy and practice and to focus international attention to deafblindness in Africa.

This has not been done before. To my knowledge, this is the first time that this is being

done. I also believe that this conference will help to facilitate the creation and dissemination of correct knowledge by facilitating improved communication and networking and to encourage improvements in the implementation of effective evidence-based practises on the issues of deafblindness.

Ladies and Gentlemen,

At the end of this two days' conference, I expect that we will have increased awareness in African countries that deafblindness is a distinct disability that must be recognised in policies and services. I also believe that at the end of this conference, we will have highlighted the work being done in Africa regarding the promotion of disability inclusion in all our social programmes. I also believe that through this conference, we will be able to develop and improve teaching and learning processes in institutions for the deafblind in different countries of Africa. I also believe that this conference will help to bring together all of us who are concerned with the issue of deafblindness. All of us who are committed to improving the condition of the deafblind, I hope, will lead to the network of individuals who are working on contributing to making life better for the deafblind.

Ladies and Gentlemen,

I speak today on behalf of the Association of African Universities, a membership organisation of over 400 universities in Africa. My plea to all of us today is this: let us give support to the deafblind, let us be the advocate for their course and their rights, let us provide them with education that will empower them, let us create the social environment that will make the deafblind to also contribute to our society.

Thank you for listening.

Establishing Minimum Standards For Inclusive Education Of Persons With Deaf-Blindness In Uganda.

Michael Sebuliba
Country Director; Edward Otim; Program Manager,
Sense International Uganda

Abstract

Despite the fact that Uganda has made reasonable strides towards fulfilling its commitments to inclusive education, there are yet no nationally established standards for the inclusion of learners with deafblindness or other learners with disabilities. Sense International Uganda (SIU) has been implementing a novel model of including children with deafblindness in education called the 2-Step inclusive education Model. In the absence of minimum education standards to guide the provision of inclusive education to learners with deafblindness in Uganda, SIU commissioned a study in 2019 to develop minimum standards of delivering inclusive education to learners with deafblindness.

The study was carried out to (i) find out the standards adopted and practised in implementing the 2-step model to ensure quality learning of children with deafblindness in inclusive settings (ii) establish the perceived costs to the family/ community and school for effectively managing a 2-step model of inclusion for children with deaf-blindness (iii) establish other extra costs for their exclusion that existed.

The study adopted a both a qualitative and quantitative approach using both secondary data (literature) and primary data from key Informant Interviews plus use of FGDs. The findings from the study emphasised areas of; Early Identification and Assessments (EIA), community sensitisation, use of Individualized Educational Plans (IEPs) and continuous assessments soon after the identification and learning needs assessment has been done, parental involvement plus government social protection programs for persons with deafblindness. The study gave recommendations that cut across; the existing legal frameworks, supportive community structures, available conducive curriculum, and adoption by government of these minimum standards to guide the learning of persons with deafblindness both at home and school.

Key words: Minimum standards, deafblindness, inclusive education.

Introduction to the Study

Deafblindness is described as the condition of little or no useful sight and little or no useful hearing; it is a combination of sight and hearing loss that affects a person's ability to communicate, access information and get around. It is also sometimes called "dual sensory loss" or "multi-sensory impairment." The causes of deafblindness include genetic conditions such as Usher syndrome, an infection in a baby in the womb such as rubella (German measles), Cerebral palsy, which is a problem with the brain and nervous system that mainly affects movement and co-ordination, or eye problems associated with increasing age, such as cataracts or age-related hearing loss. Despite the many global efforts to realize disability

inclusion, persons with deafblindness are relatively more likely to be poor, unemployed and with lower educational attainment. Educational interventions targeting persons with disabilities tend to overlook persons with significant disabilities such as deafblindness.

Background to the Study

The UN Convention on the Rights of Persons with Disabilities, (2006) which Uganda ratified on September 25, 2008, ensures that education is a right for all including learners with deafblindness. Uganda like many other states is obliged to enable persons with deafblindness to access information, communication, and other services in order to live independently and to effectively participate in society development activities. However, owing to their very small number, persons with deafblindness can easily be left behind in development programmes including education. This calls for the Inclusive Education approach. The concept of inclusive education is holistic and therefore encompasses the home and community environments.

Despite the fact that Uganda has made reasonable strides towards fulfilling its commitments to inclusive education, there are no nationally established standards for the inclusion of learners with deafblindness or other learners with disabilities. However, Sense International has been implementing a novel model of including children with deafblindness in education called the 2-Step Model. Therefore, given the fact that there were no minimum education standards to guide the provision of inclusive education to learners with deafblindness in Uganda, Sense International Uganda (SIU) commissioned a study in 2019 to develop minimum standards of delivering inclusive education to learners with deafblindness from the lessons learnt from the 2-step model implemented by SIU in 15 districts in Uganda

Purpose of the Study

To establish minimum standards for including children with deafblindness in education under the 2-step model approach and ascertain the costs of educating them. Specifically, the study was carried out to ;

1. Find out the standards adopted and practised in implementing the 2-step model to ensure quality learning of children with deafblindness and multi-sensory impairments in inclusive settings
2. Establish the perceived costs to the family/ community and school for effectively managing a 2-step model of inclusion for children with deaf-blindness; and
3. Find out the extra costs that are incurred at household and school levels in the process of including children with deafblindness in education.

Methodology:

The study adopted a qualitative approach using both secondary data (literature) and primary data from key Informant Interviews plus Focus Group Discussions to collect data. The primary target group for the study were project beneficiaries from schools and homes in the 15 districts where the 2-step model is being implemented by SIU. The major inclusion criteria in the study were; being a child with deafblindness, a parent of a child with deafblindness, a teacher from a school where children with deafblindness were enrolled at

the time of study, districts officials. However, some children without disabilities were also considered for purposes of comparing their views.

ELEMENTS OF STANDARDS ADOPTED AND PRACTISED IN IMPLEMENTING THE 2-STEP MODEL TO ENSURE QUALITY LEARNING OF CHILDREN WITH DEAF BLINDNESS AND MULTI-SENSORY IMPAIRMENTS IN INCLUSIVE SETTING

1. Learners with Deafblindness should be identified early and properly assessed, using a multi-disciplinary team that involves parents, health workers, teachers and learning needs agreed for appropriate support in the level most suitable for their optimal benefit.
2. Promoting a positive Culture and an Environment that is Inclusive and Non-discriminatory both at the home/ Community based and School based learning levels.
3. Use of Individualized Educational Plans (IEPs) and Continuous assessments soon after the identification and learning needs assessment has been done.
4. Parents of Learners with deafblindness should take responsibility to participate in their children's rehabilitation and learning
5. Government should consider the social protection of learners with deafblindness by improving access to audiology, ophthalmic, services at designated health facilities.
6. Parents should take their roles and responsibility seriously to ensure learners with deafblindness are not left behind
7. Personnel should be trained and employed in schools so that learners with deafblindness are supported well at home and at school
8. Schools and district education leadership should support their communities and staff in order to foster inclusive education at their levels.

Findings

a) The minimum standards adopted and practised in implementing the 2-step model

THE 2-STEP MODEL

Under the 2-step model of inclusive education, children with deafblindness can learn both at home and in regular schools, as well as effective home-based-learning of children who may not transition to school. The model, therefore, has the home-based and school-based levels of learning.

LEVEL 1: HOME BASED LEARNING

- The purpose of home-based learning is to adopt extra ways of learning and cross the distance to school

- The entire family including the siblings and parents support the learners at home to acquire life skills.
- Home-based learning follows a Community Based Education (CBE) curriculum.

LEVEL 2: SCHOOL-BASED LEARNING

- This level picks up from level one when all home-based skills have been acquired.
- Learners cross from home to school to attend a regular school closest to them with continued support from their parents, teachers, and assistants.
- Some learners with severe deafblindness will never cross to school but will be supported to acquire some competencies at home and be productive in their communities.

b) The costs incurred by the family/community for inclusion of learners with deafblindness/multi-sensory impairments using the 2-step model:

Home-related Costs:

The home-related costs in the implementation of the 2-step model are those majorly incurred on feeding, medication, clothing, school visitations, and transport to school and health facilities. Facilitation for support /interpreter guide visits is the most expensive cost with an average amount of 310,000 shillings per month. Other costs include one-off costs on corrective surgery and payment for assistive devices. The home-related expenses also include one-off costs like: Corrective Surgery e.g. eye surgery/cataract removal which cost between 670,000 to 1 million Uganda shillings, Assistive devices including white cane, braille machines, hearing aids cost between 70,000 to 3,500,000 Uganda shillings depending on the needs of the learners with deafblindness.

School-related costs

Expenses associated with the learning of children with deafblindness in inclusive school settings were school dues (fees, uniforms, scholastic materials, meals, medical care) and other personal costs (clothing, food) which parents incurred while taking children to school. A few parents had also had to meet the costs of learning materials and aides like reading glasses.

The school-based learning expenses also stretched a bit further to include not only for day scholars but also for children whose parents had preferred to enroll them in boarding section school which might be a special school or special unit in a regular school. The costs included payments to personnel who are trained to handle these learners and transportation where some parents testified having to incur motorcycle/ boda-boda costs on a daily basis to the tune of 60,000 Uganda shillings per week in order for their children to keep attending school.

c. The extra costs incurred at household and school levels in including children with deafblindness in education

- Besides the home-based and school-based expenses, other expenses are incurred by the government and NGOs. These are in terms of school facilities, health, skilled personnel, support staff and other assistances like technology. The resources rooms equipment are the most costly with an average cost of 19,500,000 Uganda shillings. Others are school modifications like ramps which cost an average of 10 million Uganda shillings and training teachers and teaching assistants which on average cost 800,000 Uganda shillings.
- The health-related costs are those incurred on Corrective Surgery like eye surgery/cataract removal, heart surgery, assistive devices (white cane, braille machines, hearing aids), training health staff on short-tailored courses in audiometry, ophthalmology audiometers;
- The extra resources are hard to acquire by district authorities without interventions of NGOs like Sense International.

BENEFITS OF THE 2-STEP MODEL

- Through the participatory approach, the 2-step model has enabled parents to acquire some basic skills necessary for livelihood improvement.
- The model improves communication between family members and the child with deafblindness. This helps the teachers to identify their needs and sensitize the parents
- The 2-step model improves the contact between government and donors to the families of these children
- The 2-step model provides an opportunity for the teaching professionals to support the communities around them better since it helps them to map out some good practices in the model.
- In schools where administrators have gone out of their way to foster inclusive learning for learners with deafblindness, the entire schools can adopt the positive culture and the learning could be shared amongst themselves.

Conclusion

The study found no documented minimum standards tailored for the inclusion of learners with specific disabilities such as deafblindness. Nonetheless, the study identified practices within the 2-step model, and these coupled with literature reviews both locally and from other countries enabled identification of strengths, weaknesses and opportunity for establishing standards which can influence related inclusive policies for health and education service provisions.

Recommendations:

The study found no documented minimum standards tailored for the inclusion of learners

with specific disabilities such as deafblindness in Uganda. Based on the conclusion and findings of the study, the following recommendations were proposed:

1. Learners with deafblindness should enroll and learn in the inclusive schools as long as their parents and school systems are receptive and have the extra supports they require, such as teaching staff, teaching assistants, interpreters and learning materials and can access medical care.
2. There is need to advocate for teachers who are specifically trained to handle learners with deafblindness.
3. The support to learn from home is as equally important as the support to cross to school and access the learning with others. Therefore, learners with deafblindness should be supported to identify the best learning out comes which suit their abilities.
4. Learners with deafblindness need to be supported very early to access health rehabilitation to reduce on the loss of their hearing and vision. With this, there is need to advocate to government to meet the high cost of health rehabilitation.
5. Options like skilling for crafts, farming and other competencies instead of numeracy and literacy only as learning goals should be emphasized early and even adopted and popularized by government as an alternative Community Based Education curriculum
6. Government should adopt minimum standards proposed in this study to guide the learning both at home based and, in the school, based settings of learners with deafblindness.
7. Government should increase the capitation grants for individual learners in order to help schools meet the costs of educating learners with deafblindness in inclusive schools. The current government contribution of 12,000 Uganda shillings per child per year should be increased to at least 100,000U Uganda shillings per child per year.
8. The government should support teaching assistants with at least 300,000 Uganda shillings per month to provide the 1:1 support for learners with deafblindness, given that the teachers are not adequate, and classes crowded.

References:

Hilton/Perkins Program, 2001: Competencies for Paraprofessionals Working With Learners Who are Deafblind in Early Intervention and Educational Settings.

Glavin, Chris (2014). Standards -based Education Reform-K12 Academics.

- UNESCO. (2005). *Guidelines for inclusion: Ensuring access to Education for All*. Paris: UNESCO.
- Ainscow, M. & Miles, S. Prospects (2008) Inclusive education: Open debates and the road ahead.
- John W. Reiman Pattie A. Johnson, 1993, Proceedings of the National Symposium on Children and Youth Who Are DeafBlind.
- Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods*, 3rd edition. Thousand Oaks, CA: Sage Publications.
- Lwanga-Ntale, C., & McClean, K. (2004). The face of chronic poverty in Uganda from the poor's perspective: constraints and opportunities. *Journal of Human Development*, 5(2), 177-194.
- The Global Deafblindness Report, AT RISK OF EXCLUSION FROM CRPD AND SDGS IMPLEMENTATION (2016).
- Uganda Bureau of Statistics (2014). Population and Housing Census report.
- UNICEF (2014). *Situational Analysis on the Rights of Children with Disabilities in Uganda*. Kampala: UNICEF.
- Bannink, F., Idro, R., and van Hove, G. (2016) Teachers' and parents' perspectives on inclusive education for children with spina bifida in Uganda. *Journal of Childhood & Developmental Disorders*, 2:10.
- Ejuu, G. (2016). Moving in Circles along a Straight Path: The Elusiveness of Inclusive Education in Early Childhood Development in Uganda. *Journal of Childhood & Developmental Disorders*, 2(1).
- Ojok, P. & Wormnaes, S. (2012). Inclusion of Pupils with Intellectual Disabilities: A Survey of Primary School Teachers' Attitudes and willingness in a Rural Area in Uganda. *International Journal of Inclusive Education*, 17 (9), 1003-1021.
- Nyende, F. (2012). *Children with Disabilities in Universal Primary Education in Uganda: A Rights-Based Analysis to Inclusive Education* The Hague: Institute of Social Studies.
- Enable-Ed& USDC 2017. A mapping of Inclusive Education

Determining Barriers To Education And Transition Of Children Who Are Deafblind, Kwale County

Joyce Ng'ara

Teacher, Kwale Special School For The Deaf - Unit For The Deafblind, Kenya

ABSTRACT

Deaf blindness is the combination that creates severe communication challenges, and other developmental and educational necessities. Thus, the inability to effortlessly obtain information via the long-distance senses of hearing and eye sight hence the impact on their capability to interact with others and obtain knowledge about the environment around. This has imperative educational insinuations for these children since they subsequently require distinctive instructional techniques and tactics to learn, communicate, develop concepts, gain mobility, and acquire an independent living, academic, and vocational skills.

Learners who are deafblind are unique people with diverse necessities for learning, communication, and environmental access. They are one of the lowest incidences yet most diverse in Kwale County. There have been incidences of children and youth who are deafblind taking a very long period in transiting from one level of education to the other. This study intends to explore the barriers to education transition of children who are deafblind in Kwale County. The main aim being the identification these barriers and provide possible solutions that can be implemented to tackle this problem for future smooth education and transition. This study will implement the use of interviews and filling of the questionnaires by the targeted stakeholders as the main methods to obtain the information necessary to accomplish our objectives. By the end of the study, we hope to find the critical issues that cause the hindrance to the smooth education and transition of most children who are deafblind in Kwale County.

CHAPTER 1

INTRODUCTION

Background Information

Children with disabilities have an essential right to education just like any other children, as delineated in several International and National legislative and policy instruments. In Kenya, article 54 of the constitution specifically targets people with disabilities. The constitution provides that persons with disability have a right to access educational institutions and facilities that are assimilated into society to extent compatible with their interests and needs (GOK, 2010).

According to a study conducted by the Sense International Kenya (SIK), there are about 17,000 people with deaf blindness in Kenya. Although the figure looks small compared to the Country's population, they still need intervention and support for their future independent living. One of the supports required is education as prescribed by the constitution of Kenya. However, education transition for children who are deafblind has

become the most precarious issue in Kwale County and the country at large.

Many studies which have been conducted in Kenya focusing generally on the rights to education, curriculum development and transition plans for children with disabilities. The National Gender and Education Commission (NGEC) 2016, conducted a survey with the objective to assess the extent to which Universal Primary Education is accessible to children with disabilities. In 2010, John K Mugo and Josephine Oranga of Kenyatta University partnered with the Cambridge University through Nidhi Singal conducted a study that aimed at evaluating whether children with disabilities were transiting in various areas of their studies. They found that young adults with disabilities were dwindling through the cracks of the various barriers surrounding their environment.

The Ministry of Education desired to accomplish full education access, retention and smooth transition for all children comprising those with disabilities and special needs in education. To accomplish this, reliable data is essential to direct policies, planning and resources for special needs education. Therefore, Kenya Institute of Special Education, Ministry of Education and Kenya National Bureau of Statistics joined forces to conduct the national survey on children with disabilities and special needs in education in Kenya, 2017. However, this did not specifically target children with multiple disabilities, deafblind and visually impaired (MDVI). Thus, it has become apparent that little is presently acknowledged about educational transition for children who are deafblind in Kenya.

The study in this report therefore was conducted with the aim of identifying the barriers to education and transition of children who are deafblind in Kwale County. The results of this study will enable various institutions in the County and the Country at large in implementing the possible solutions for the smooth education and transition of children who are deafblind.

1.2 Research Problem

In the recent past, Kwale School for the Deaf, unit for the deafblind had seen a remarkable good number of early enrollment of children who are deafblind. This had improved specifically due to the awareness and sensitization programs that have been conducted in the County. However, the transition of children who are deafblind had barely been a success since just a small percentage of the students' transit to the Vocational training institutions for advancement in their independent living skills. Moreover, there has been a lack of early intervention programs which made it difficult for good developmental and educational skills hence the barriers to their education and transition.

1.3 General Objective

The main objective of this study was to determine the barriers to education and transition of children who are deafblind in Kwale County.

1.31 Specific Objectives

1. To determine whether understaffing hindered the education and transition of

children who are deafblind.

2. To assess the barriers to education and transition of children who are deafblind in Kwale County.

1.32 Research Questions

1. Is understaffing the reasons that hindered the education and transition of children who are deafblind?
2. What are the barriers to smooth education and transition of children who are deafblind in Kwale County?

1.33 Justification

This study will help identify the barriers to education and transition of children who are deafblind. Also, the study will look for possible solutions to enhance smooth education and transition for majority of the children who are deafblind.

1.4 Research Methodology

The study employed the use of questionnaire as the main method used to conduct the research. Unfortunately, due unavoidable circumstances I was unable to conduct a face-to-face interview. Some of the questionnaires were distributed to the available concerned stakeholders and some were marked through phone calls to the willing participants.

In total, 15 questionnaires were used according to the number of children who are deafblind and those stakeholders that were willing to participate.

CHAPTER 2

LITERATURE REVIEW

Transition is the alteration or movement from one concept, position, stage, state or subject to another. The term transition generally refers to three key events; when learners move from home or pre-school to primary school, from primary school to secondary school, and from secondary school to tertiary education like vocational training, colleges and university. Children also experience a number of other important transitions during their education, such as moving, usually annually, from one class/grade to the next within the same school, or changing schools when their family moves to live in a different place (Bridge of Hope, 2015). Internationally, there has been a continued and increasing interest by governments and researchers in how transition from one level of education to another in late childhood or early adolescence impact the children's educational and wellbeing outcomes (Symonds and Galton, 2014; Jindal-Snape and Cantali, 2019; Jindal-Snape et al., 2020).

Chapter 3

RESULTS AND DISCUSSIONS

The discoveries summarized here were occasioned from the numerous focus group interviews and researches. They provide a snapshot of sentiments and experiences associated to transition between grades/schools for children who are deafblind. Over the

past 9 years, the department of deafblind has seen a good number of children who were enrolled in the unit. In total, there were about 22 learners from the past 9 years. Out of this number, just 4 learners transited to SKRI Vocational Centre. Since 2019, the school has never managed to transit any student. These figures are worrying if you compare the number of students who were enrolled with the number of learners who transited. A good number of these learners dropped out of school and some were faced by other calamities. Currently, the unit has 13 learners and so far this year only 3 have managed to be transited. The following were concluded as the barriers to education and transition of children who are deafblind in Kwale Special School for the Deaf and unit for the Deafblind.

Under Staffing

According to the educational approach of children who are deafblind, the ration of teachers to learners should be 1:1. However, this is not the case in Kwale County. As per the information provided by some of the teaching staff at Kwale Special School for the Deaf and unit for the Deafblind, the ratio of teachers to learners is 1:3. This has caused slow progress in teaching the learners various skills since the teacher has to deal with 3 learners at once which makes it difficult. As a result, learners take long to transit from one level to another due to slow acquisition of skills. Thus, under staffing is one of the barriers to smooth education and transition.

Change of Environment

There have been sensitization programs which were conducted in the county about early enrollment of children who are deafblind. This has seen significant adoption by many parents with children with disabilities in the county. However, about 60% new comers enrolled in the school experience difficulties in sudden environmental and dietary changes. This was seen as a barrier especially to those newly enrolled children who are transiting from home to school hence long time is spent on them for adjustment to the new environment and diet. Out of the total respondents just 40% had little or no challenges. Also, there are changes in the sleeping patterns where most students were observed staying up all night and become sleepy during classwork.

Poor Communication Skills

Newly enrolled children are faced with a communication barrier due to poor communication skills. About 99% of Children who are deafblind experienced difficulties in understanding the sign language and tactual signing for ease in passing information. Hence, newly enrolled children are biased for proper communication which sometimes takes long for them to understand how to communicate with their teachers, their peers and house parents. Therefore, poor communication skills were seen as barriers to smooth education and transition of children who are deafblind.

Humble Backgrounds

According to the information we acquired, about 80% percent of the children who are deafblind came from humble backgrounds families. This was observed as most children

were faced with malnutrition challenges when they are being enrolled in the school. Malnutrition causes several health challenges including poor brain development and are prone to other diseases due to poor immunity. Also, children from humble backgrounds experience difficulties in accessing some school necessities which are required for comfortable education. The family status of these children was seen as a barrier to smooth education and transition since they are faced with economic challenges.

Dropouts

The unit for the deafblind has experienced several dropouts and young adults who transit from school to home. In total, around 6 learners dropped out of school due to lack of funds for their education and necessities. Also, parents who see no progress in their children's transition from one level to another end up discontinuing their children. There were also some cases of health issues which made it impossible for the children to continue with their studies. Hence, dropping out by learners was seen as a setback to education and transition

Social Life and Relationships After Transition

In recent past, about 6 learners have been transited home. This was due to observations made by the teaching staff where the learners were not making any progress in acquiring skills for their independent living. Moreover, the young adults were further faced with challenges when they reach home. These young adults were faced with discrimination and negligence from both the family and the society hence less attention was given to them as they are seen as liabilities. Therefore, social life and relationships after transition was concluded as a barrier to smooth education and transition.

Conclusion and Recommendations

For the education and transition process of children who are deafblind to smoothly bare fruits. Addressing the above barriers is necessary for effective smooth education and transition. There have been inspiring success stories of young adults who transited and are now well-off in terms of their independent living. This can be achieved more if the following recommendations are addressed.

1. Increasing the number of teaching staff in order to meet the 1:1 ratio in the units for the deafblind of various institutions in the country.
2. All children who are deafblind should be registered under Kenya National Council for Persons with Disability (KNCPD) to access cash transfer.
3. Creating job opportunities to those families who are from humble background so that they can be economically stable and cater for their family needs.
4. Revival of the community-based education (CBE).
5. Orientation should be done to the identified children who are yet to be enrolled to the school for familiarization with the school environment.

REFERENCES

1. Jindal-Snape and Cantali, 2019; Jindal-Snape et al., 2020
2. The National Gender and Education Commission (NGEC) 2016

3. Bridge of Hope, 2015.
4. Symonds and Galton, 2014.
5. 2 EENET, 2011, 'A team approach to inclusion, Macedonia', 2011, p.2.
6. The constitution of Kenya (GOK, 2010).
7. John K Mugo and Josephine Oranga of Kenyatta University, Nidhi Singal (Cambridge University), 2010.
8. 9 Krishnakumar, P. (2009) 'Early Childhood Care and Development for All in Sri Lanka' in Enabling Education.

Prospects And Challenges Of Educating A Deafblind Student In A University In Ghana

Dr. Daniel S. Q. Dogbe

Senior Lecturer, University of Education Wineba, Ghana

Francis Anku

Assistant Lecturer, University of Education Wineba, Ghana

INTRODUCTION

- With the adoption of the Agenda 2030, governments all over the world have focused on leaving no one behind in all facets of life, including education.
- Deafblindness is a combined vision and hearing loss in varying degrees that limits activities of a person and restricts full participation in society.
- Provision of quality higher education eludes many learners who are deaf-blind on the African continent (Richler, 2005; Lynch et al, 2014; Aesop et al, 2007; Baker et al, 2010)
- The Department of Special Education in the University of Education, Winneba (UEW) trains educators of learners with special needs: blind and/or low vision, the deaf, hard-of-hearing and intellectual disability.
- In 2017, UEW undertook a flagship project to include, for the first time, a qualified deaf-blind student in the Department of Special Education.
- Challenges of implementing Inclusive Education (IE) in Ghana have been widely documented in the literature, such as in the works of Hayford (2013); Avoke (2004); Gyimah (2008); Ocloo, Dogbe, and Gadagbui (2010); and Gadagbui (2012).
- Gaps still exist in the implementation of the IE Policy and ultimately Universal Design for Learning (UDL), which have negative consequences for both the deaf-blind learner and the educator.

The purpose of the Study

To find out the challenges experienced by all stakeholders (with special reference to the learner with deafblindness and the lecturers) and suggest solutions to address them.

Research questions

- What are the experiences of the deaf-blind learner and the lecturers

of the learner who is deaf-blind?

- 'Describe the barriers of teaching a learner who is deaf-blind'
- 'What are the enablers of teaching a learner who is deaf-blind in a university like yours?'
- 'What kind of support structures are available to lecturers of the deaf-blind learner?'
- 'What are your experiences of pursuing university education in this institution?' and
- 'What are some of your challenges in the pursuit of higher education?'

Methodology

Design: Exploratory Qualitative Research

Setting: University of Education, Winneba (UEW), Department of Special Education

Participants: Fourteen (14) stakeholders comprising (Male = 8; Female = 6; Age: 21 – 59 years)

Sampling technique:

Purposive

Instruments: Semi-structured interviews and observation

Trustworthiness: Credibility, transferability, conformability and dependability

Data Analysis: inductive thematic procedures – familiarization, coding, searching for themes, reviewing themes, defining and naming themes and reporting processes.

Results and Discussion

lack of knowledge and understanding about deaf-blindness, communication challenges, inadequate preparation of educators/teachers and resource persons,

lack of support structures for all stakeholders particularly, special education lecturers and resource persons, and time-consuming nature needed to educate the deafblind learner.

Early Screening, Intervention and Transition To Inclusive Education For Children With Deafblindness And Those With Complex Disabilities In Kenya

Richard Mativu
Country Director, Sense International, Kenya

Mellen Marucha
Programs Officer, Sense International, Kenya

Faith Nyaboke
Programs Assistant, Sense International, Kenya

INTRODUCTION

- We support government health systems to offer ear and eye screening, and occupational therapy. Screening starts with Community Health Volunteers administering a risk factor identification questionnaire and referring on.
- We support children with Deaf-blindness to learn in a nearby mainstream school with a Learning Support Assistant (LSA); a new concept in Kenya.
- We have worked with the Ministry of Education and the Kenya Institute of Curriculum Development (KICD) to agree a LSA curriculum and introduce a new cadre of training in the Kenya Institute of Special Education.

Thematic Areas

Early identification and intervention

Inclusive education- Learner support assistance (More than 100 hired)

Vocational skills- Most learners do/not transition to secondary and vocational institutions.

Seeking partnerships and support to sustain different programs

Partnerships: Kapsabet, Kilimanjaro, Maseno, Kilifi etc

Community based education: Learners are supported at home in learning

Training of the vocational skills.

Notes: Early identification and Intervention Types of screening

1.

Community level volunteers are trained on screening- ears from as early as 24 hrs after birth. What happens after the identification

Referral and follow up

Stages

Awareness

Capacity development

Screening

Assessment

Intervention

Reassessment
Transition

Good job: How long has this been in existence and what are the successes

Transitioning: Placement in the ECD -Location, factors, human resource, where
Which are the available centers in Nairobi

1. INCLUSIVE EDUCATION

Transition into schools

Home based education:

Activities of daily living
Inclusive education with learning support assistants
Accessibility
Qualified human resource
Learning materials
Parental engagement
Sense supports the schools to take care of the above issues
Learning Support assistance
Not trained as a teacher
First cohort of assistants - Learning assistance graduating this yr.
Every Learner has an IEP that's completed by the IEP team including the parent
What support do you offer to/parents of these children?

Achievements

1. Screened
242. Early intervention
500. CHVs, Nurses, and Clinical officers trained

Findings

Skill development amongst the learners getting schooling at an early age
Increased enrollment and retention
Change of attitude amongst parents
Importance of using accessible content at home

Recommendations

Importance of early screening and interventions
Got to recognize the role of LSA and allocate funding
More teachers to be trained on inclusive education
System mapping and interventions and localize the service

Create more awareness and agency

Challenges: Embracing Attitude

Questions

*Are the EARCS equipped to support learners with DB
Advise on inclusion of learners with deaf blindness*

Deafblind People Taking Part In Southern Africa: A Delphi Study Looking At Stakeholder Views Of AT Outcomes

Dr. Diane Bell

Academic, Cape Peninsula University of Technology, South Africa

Ms Ilana Hermez

Person with Deafblindness, South Africa

Introduction

We know that people with disability experience disadvantages in socio-economic and employment status, and lower overall health status. Assistive technology (AT) is a key enabler of improved outcomes for people with disabilities, including those with deaf blindness in all life domains. But tools are needed to assist people with disabilities to articulate their needs, goals and rights related to the use of AT, and to evaluate and measure AT- related outcomes. This is needed in order to make the case for the appropriate AT provision.

Background

Assistive technology according to the World Health Organization (WHO), is an umbrella term for assistive products and related services. Using AT maintains or improves a person's ability to function and be independent, thus promoting their wellbeing. It includes devices, equipment, instruments, and software. Deaf blindness is a unique and isolating sensory disability, resulting from both hearing and vision loss that significantly affects communication, socialization, mobility and daily living.

Deafblind individuals make use of AT to overcome these functional limitations, such as using long canes, cochlear implants, braille displays, as well as human supports such as sign language interpreters. The Southern African Development Community, (SADC) was selected as any research into AT and its impact must be sensitive to context and the impact of context upon capability. Also, there is an emergence of an act of Pan African AT community and evidence of strategic thinking about AT systems within the region. Prevalence figures of deafblindness on the African continent are not available, but evidence suggests that in low- and middle-income countries, only five to 15% of people who require assistive devices receive them. There is also a lack of research in this field.

AT outcomes research looks at the changes produced by AT in the lives of users in their environments. Despite calls for the collection of AT outcomes data, it is still not generally collected, and there is no consensus on the priority dimensions to be collected. My AT Framework or My AT outcomes Framework could be an alternative starting point, which provides AT users and stakeholders access to a co-designed, evidence-based and holistic set of outcome dimensions for two primary reasons: Firstly, many AT outcome measurement tools only collect partial information, and most tools are not designed to be consumer directed.

The My AT Outcomes' Framework is a novel Australian framework and an online tool founded upon AT process principles and outcomes research. It guides stakeholders to articulate their AT use according to six dimensions; Firstly, my supports, secondly, my outcomes, thirdly, my costs, fourthly, my rights, fifthly, My AT service delivery pathway, and finally, my customer experience. It was devised to capture the AT users' perspectives across these dimensions and comprises a set of questions which summarize information at the AT users' needs, goals and context so that the AT user is enabled to inform practitioners and funders regarding a need for specific AT. Data are summarized into report formats enabling, the AT user to inform their practitioners and funders regarding their specific need for a specific AT

Study Aims.

The use case of assistive technology by people with deafblindness in southern Africa, was investigated in the study to determine the applicability of the My Assistive Technology Outcomes Framework (MyATOF) dimensions to people with deafblindness living in low- and middle-income countries. There were three key aims; Firstly, to determine the relevance and face validity of the MyATOF for use with people with deafblindness in the SADC region; secondly, to refine the tool to increase its relevance and validity in this context; and thirdly, to deepen the understanding of the context of AT provision and use by people with deaf blindness in the SADEC region.

Materials, Methods and Analysis

The Delphi methodology was chosen to achieve consensus among the expert panel, and since it integrates elements of both qualitative and quantitative methodologies, it yields a more holistic view of the research issue under investigation. 96 experts were identified with two online surveys being conducted. 17 experts from four countries responded in phase one, and 14 in phase two. A heterogeneous, e-Delphi expert panel, representing the diverse stakeholder group across the field of deafblindness in the SADC region was selected. The criteria of eligibility to participate in the study were; people with deafblindness over 18 years of age, family members of people with deafblindness, educators with a minimum of three years' experience working in deaf blindness, researchers with a minimum of three years' experience working in the field of deafblindness, service providers also with a minimum of three years' experience, and representatives from advocacy groups, who also had a minimum of three years' experience in working with people with deafblindness. The data was analyzed using the WHO's 5P AT Systems Thinking Model.

Data Collection

Use was made of the Qualtrics online survey software which provided a secure and accessible platform to capture consent and survey responses. Three participants requested MS Word versions of the survey and returned these via email with the first author manually capturing this data within the Qualtrics system.

Timeline for Data Collection

Essentially, from the pilot study to the completion of Phase two took an average of 12 weeks during the year 2020 with completion being in December at the end of that year. The pilot study took two weeks; the selection of the Delphi expert panel three weeks; phase one took another three weeks; and phase two another three weeks culminating in 12 weeks.

Data Analysis

Each Delphi round was both quantitative and qualitative in terms of its analysis. With the qualitative analysis, we made use of a thematic inductive approach and we mapped the data against the WHO's 5Ps related to assistive technology. For example, cost and lack of availability of assistive technology was captured by products and policy; two of the WHO's 5Ps.

Phase 1: Results; A Few Quotes:

So, for phase one, the tool A which related to My supports: The panelists described the use of AT as enabling the achievement of outcomes and endorsed and expanded the subset of products and here, we have a number of quotes: One participant indicated that "assistive technologies have played a pivotal role in helping the deafblind", A second quote, "In most cases, deafblind do not have access to AT making their lives difficult and unbearable. The third quote; "AT is only available to those who can afford it. Government is not set up for AT". And the fourth quote; "It is vital for the deafblind persons to be familiar with the CRPD as an advocating tool". So, these quotes came from the different tools within the My AT Outcomes Framework.

With regards to the results of phase two, panel members were invited to identify the level of importance that each of the 20 somethings derived from the Phase One data held for addressing the AT needs of people with deafblindness in the SADC region and six out of the 27 themes were viewed as very important. These were raising awareness of deafblind people about social inclusion, number two, government must implement the CRPD, number three, governments should make AT that is relevant to people with deafblindness available, number four, governments need to play more of a role in AT provision, number five, there is a need for staff awareness about deafblindness and skills development in general health and disability services; and number six, there is a need for staff awareness about deafblindness in all areas of government and social services. With regards to the overall findings, aim one which was how relevant and valid is My ATOF for use with people with deafblindness in the SADC region and year it was found that the My ATOF dimensions are 100% relevant and they hold face validity and are suitable for people with deafblindness in four SADC countries.

Aim two; what refinements to the My ATOF might be required to increase its relevance and validity in this context? The finding was that the My ATOF does not require refinement in its dimensions but needs to foreground a person's context. For instance, specifying and naming the impact of systems upon a person. And three, what has been learned about the context of AT provision and use by people with deafblindness in the SADC region? And here, the

findings indicated that in terms of WHO's 5P's and the people:

- the tool is user-centered and policies, it refers to laws, implementation, and funding that is required for AT and AT products;

- that there is a lack of supply in terms of obtaining products;

- that there is a need for local production; for the removal of import barriers and cost reductions to ensure availability; and

- there's also a need for high quality fit-for-purpose products which are needed.

With regard to provision, Panelists supported the call for universal access and early intervention and a single point-of-service using innovative models; And then with regards to personnel, the panelists agreed with the WHO on the need for widespread training for people with deafblindness and their families, as well as civil society and professionals that articulated the need for specific training of personnel in deafblindness, for example, in various communication methods.

The main conclusion of the study was that the mind at outcomes framework tool, with its six dimensions shows promise in its use with persons with deafblindness in the SADC region to realize their rights through self-advocacy.

Some insights: The use of assistive technology by people with deafblindness in Southern Africa was investigated in the study to determine the applicability of the My AT Outcomes Framework dimensions to people with deafblindness living in low- and middle-income countries. There were three key ends and the insights from the study indicate the following the impact of at and related support can be evaluated across a number of dimensions. Secondly, these dimensions resonate across two vastly different continents. Thirdly, variables influencing access to at across contexts can be understood through the WHO gate five P's systems thinking model. And finally, few tools place data capture and outcomes measurement in the hands of the 80 users. Some evidence that this is a value to consumers.

And in conclusion, this quote is taken from the Global Disability innovation hubs, Disability Strategy for the period 2021 to 2024. And I quote, "A More Inclusive World is a More Sustainable World, and it is Possible".

I thank you on behalf of all the researchers, and I thank deafblind international for the funding for this project.

Towards Equitable Access To Public Information And Communication By Persons With Deafblindness in Uganda. A Case Study Of COVID-19 Information

Dr. Aniyamuzaala James Rwampigi
Researcher, University College Dublin, Ireland

THE BACKGROUND:

Approximately 2% of the global population are Persons with Deafblindness (WFDB, 2018); Persons with Deafblindness above 18 years were approximately 0.01 or 411,700 People of Uganda's population. No official reliable data (UBOS, 2017); face multiple barriers including information communication and mobility barriers (WFDB, 20).

The Statement of the Problem:

Persons with Deafblindness were excluded in the COVID-19 Interventions (IDA, 2021); 1995 Constitution of Uganda protects and promotes right to access to information; The 2005 Access to Information Act do not define accessibility requirements; The 2020 Persons with Disabilities Act do not define Accessibility requirements;

The Research Question:

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?

Accessibility Requirements and Specification:

The Accessibility requirements:

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 (EU, 2019).

The Accessibility specifications:

Descriptions of the solutions, services, products, environments, facilities and others that meets the minimum accessibility requirements for Persons with Deafblindness (ETSI, 2021; EN301549).

Methodology:

The Mixed Research Methods:

Qualitative structured interviews and observation used to collect empirical data

Quantitative analysis was based qualitative data and supported qualitative analysis.

The Case Study Research Methods:

Case study of COVID-19 Information.

Research Challenge:

The COVID -19 longest lockdown in Uganda.

Data collection took a lot of time. Extra costs were incurred due to poor living conditions of some of participants. One of the researchers collecting data died during COVID-19 Lockdown.

Results:

Persons with severe hearing and sight loss depended on Care takers to access information and communication and support.

One of the Caretakers 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”.

Persons with moderate to severe hearing and sight loss used Smart phones, sign Interpretation, Hearing aids, television, magnifiers and care takers to access information and communication.

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”

A Representative of the National Council for Persons with Disabilities stated that “Government does not have a specific national policy or guide on Accessibility for persons with Disabilities. There is a national Policy on Disability that guides the inclusion of all Persons with Disabilities including Persons with Deafblindness”. 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”.

Recommendations:

Development of the national accessibility guide and standard that defines the accessibility requirements and specifications respectively; Review the existing legislations to domesticate the right to accessibility and define the accessibility requirements for Persons with

Deafblindness; Organizations of Persons with Deafblindness should be both service provision and advocacy organization.

Reference:

ETSI, 2021, EN 301549, Accessibility requirements for ICT Products and services

European Union, 2019, European Accessibility Act, EU Directive 2019/2019; Accessibility requirements for Products and services.

IDRC-OCAD University, 2018, what is inclusive Design, <https://idrc.ocadu.ca/>

Leeds-Hurwitz, W. (2009). Social Construction of Reality. In S. Little john, & K. Foss (Eds.), Encyclopedia of Communication Theory (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>

Robert Yin, 2018, Case study Research.

Sense International, 2021, Population of the persons with Deafblindness in Uganda.

The IDA, 2021, The Survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic

Uganda Bureau of Statistics (UBOS), 2014, Uganda Population and Housing Census Report

Uganda Bureau of Statistics (UBOS), 2017, Uganda Functional Difficulties Report

Uganda, 1995, The Constitution of Republic of Uganda; article 41

Uganda, 2005, Access to Information Act.

United Nations, 2006, Convention on Rights of Persons with Disabilities.

WFDB and Sense International, 2018, At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deaf blindness.

Meeting The Problem Of Affordability Of Technical Means For Communication And Access To Information

Fedor Belomoiev
CEO, 4Blind

Abstract

4Blind conducts research on accessibility of information and communication to people with simultaneous absence of vision, hearing and speech and about protection of their privacy then creating technologies solving problems of this community. There were more than 15 tests based on the following organizations supporting blind and deafblind people: Helen Keller National Center for Deaf-Blind Youths & Adults (USA), Massachusetts Commission for the Blind and many others. We will introduce the technology which allows a deafblind person to speak in a synthesized voice and to “hear” the interlocutor's speech due to speech recognition and synthesis provided by Google. Moreover, it allows to get unhindered access to content of computer or mobile phone. Also, we will tell a story of deafblind engineer of 4Blind who created the technology and talk about his contribution to the development of deafblind community. Since the technology is already in use today, we will talk about significant changes, which have happened in life of deafblind people, starting with ensuring their privacy through the ability for direct communication without third parties in cases that required the interpreter's assistance before, such as appointment with doctor, lawyer or bank employee, and ending with extension of their social networks because of an ability to talk to people that don't know the finger alphabet. Also, we think it is important to pay attention to main technology benefit, which is low production cost that allowed to reduce the market cost by 6 times compared to Braille Display. This will make technology affordable in developing countries.

The Problem

Today in order for a deafblind person to communicate with people, he needs to use the services of an interpreter who knows the finger alphabet or ask for the help of a relative who knows the finger alphabet or understands his speech or use a Braille display device connected to a computer or mobile device that allows to communicate in text format.

Thus, the limited means for communication today lead to the following issues:

- 1) Deafblind people do not have independence in communication and everyday life, they must always have an assistant nearby.
- 2) They have a lack of confidentiality of communication, for example, when communicating with a doctor, lawyer or bank employee due to the need to seek the help of a specialist or assistant for auditory communication.
- 3) Deafblind people have insufficient opportunities for socialization, limited access to education, professional development, and employment.

Our Research.

All these mentioned issues and the lack of technical solutions led our team to look for a communication tool that could solve these problems.

We have been doing research for 4 years. Our main goals were to make a technology that will make it easy to communicate independently with any person at any time. This technology should be easy to use and should be inexpensive to manufacture.

Technology

The result of our research and engineering developments is the world's first communicator based on Google technologies that allows a deaf-blind person to speak in a synthesized voice and hear the speech of the interlocutor.

The performance of these functions of the device is carried out by receiving and transmitting information according to the Braille principle.

The message is transmitted by pressing the six main buttons on the front panel, which are located according to the Braille principle, the received signals are converted into text and voiced to the interlocutor.

Reception of messages by the user is carried out by converting the speech of the interlocutor into tactilely perceptible vibration signals coming through the same six buttons.

In simple terms, you say a phrase, the program recognizes it and instantly transmits it with tactile vibrations to 6 buttons. The user read it tactilely and understands what you told.

In order to answer, a deafblind user presses the same buttons, the program synthesizes this into speech, and you hear what message was entered.

That is: "Text to speech", "Speech to text".

The device implements a technique in which each of the six buttons on the main keyboard corresponds to a specific number of points from No. 1 to No. 6, forming a Braille letter, and button combinations correlate to a specific Braille character.

The principle that underlies the operation of the communicator allows it to be used by various categories of users.

In addition to deafblind people, the device is used by people suffering from speech impairment or lack of speech due to stroke or aphasia, as well as people with hearing and speech loss, in order to be able to carry out situational communication.

In addition, among the users of the device there are people with low finger sensitivity, they can communicate without having to recognize the Braille dots, but only knowing its principle.

Also, among the current users there are people who are hard of hearing, who find it difficult to communicate using a hearing aid and at home, and they use a communicator.

At the heart of the created device, we use Google technologies. Thus, the reception of messages from the interlocutor occurs by transcoding the voice information of the interlocutor into silent tactilely perceptible signals using the Google speech recognition function.

In turn, the user's response, entered in Braille is voiced to the interlocutor due to the function of the speech synthesizer.

Working with Google, we also see that we can empower deaf-blind people not only by using speech recognition and synthesis technology, but also by using the translator function. Thus, we will be able to break another barrier in communication — language. In the future, a deafblind user will be able to easily communicate with a foreigner by simply changing the language of communication in the mobile application and one won't have to know a foreign language.

Watch a video of a deafblind user communicating using the device.

Sergey Fleytin's story.

In the video, one of the developers of the communicator, our employee — Sergey Fleytin. He has been deafblind since the age of 14. He was born in Estonia and went to boarding school in Latvia up to 23 years old.

The user interface and design were created according to his ideas. He makes the devices exactly the way he would like to use them himself.

Today he provides training on the use of the communicator around the world.

Testing and pilots.

Conducted pilots have shown the effectiveness of the device.

We have conducted multiply tests and pilot programs in a number of the largest specialized organizations in different countries, including:

- Helen Keller National Center for Deaf-Blind Youths & Adults (New-York, USA)
- LightHouse for the Blind and Visually Impaired (San Francisco, USA)
- Massachusetts Commission for the Blind (Boston, USA)
- National Braille Press (Boston, USA)
- Ire-AT Vision Aids for Macular Degeneration (USA)
- School Health Supplies (Illinois, USA)

During pilot programs:

- we have confirmed the effectiveness of the device;
- identified characteristics requiring improvement;

- assessed the possibilities of implementing a device for employment of deafblind people.

During the pilots, the technology received recommendations stating that it greatly contributes to the empowerment of deafblind people, their integration into society, and also provides access to education and employment.

Conducting tests and pilots showed the following results, in which three key indicators can be distinguished:

On average, it takes a user 1 to 2 minutes to learn how to use the device if they were previously familiar with Braille.

On average the user can type 35 words per minute.

The average speech comprehension is 46 words per minute.

We have already begun training on how to use the Communicator, and today more than 80 people are using the device.

As a result of the training programs, it became clear that deafblind users need additional training in the use of the principle of transmission and reception of tactile signals used in the device.

With this in mind we have developed a special training simulator that allows to train a deafblind user faster and more efficiently due to the fact that the program allows a teacher or assistant of a deafblind person to track the buttons pressed to enter the Braille characters. It displays the pressed buttons on the mobile phone screen and using certain colors for correctly or incorrectly pressed buttons.

Thus, the simulator provides:

- The ability to give specific tasks to the learning user to complete them.
- Ability to track errors when the user presses buttons to enter the desired letter.
- Faster and easier adaptation and perception of transmitting tactile signals based on Braille principle.
- The ability for the user to read not whole words and phrases, which can be difficult, but individual letters and numbers.

Additional features.

In addition to the need to introduce a training simulator, based on the results of testing, we did a lot of work on calibrating the device for different users. Depending on their level of training, experience and other indicators, different modes of interaction with the device are needed. That is why we have introduced different modes for the speed of signal

transmission to the buttons — from slow to fast, as well as the vibration strength when transmitting the words of the interlocutor — from maximum to minimum. In addition, we have introduced different modes of the interlocutor's word transmission regime from sequential to simultaneous.

What will Change.

Observing the results that the use of this communication tool shows, we can say that its use will lead to the following changes:

Barriers in communication will be destroyed and the level of socialization of deafblind people increase, providing equal access to information and social activity.

The level of independence of deafblind people in everyday life, communication and movement will increase

The privacy of deafblind people will be protected. For example, when communicating with a doctor (Confidentiality of certain medical documents), at a bank (Bank Secrecy Law), with a lawyer (Attorney's client secrecy).

Finally, opportunities for deafblind people to access education and work will expand.

In conclusion, I would like to thank all those people and organizations that support deafblind people.

We want, of course, to say thank you to those organizations that tested our technology, conducted pilots, and gave recommendations. More than 200 tests were carried out in cooperation with various organizations

We also want to thank Google for the opportunity to use speech synthesis and recognition technology. We hope that soon every deafblind person will have access to independence in communication

DAY 3: SATURDAY, 14TH MAY 2022

KEYNOTE SPEECH - FUTURE OF DEAFBLIND SERVICES IN AFRICA

Yetnebersh Nigussie Molla
Program Specialist, Children with Disabilities
UNICEF, Eastern and Southern Africa Regional Office, Ethiopia

- There are nearly 240 million children with disabilities globally according to a recent UNICEF global report on children with disabilities.
- The disability prevalence in Africa is higher than all the regions; (10.4% in Eastern and Southern Africa and 14.9% in West and Central Africa)
- Deafblind children constitute a significant number and most of them reside in developing countries including Africa.
- UNICEF works to promote the rights and wellbeing of all children including deaf blind children.
- The 4 points I want to talk to you today are Data, Enabling environment, Alliance, and Finance (DEAF)
- Data is the first and very crucial step for the inclusion of deafblind children. We measure what we treasure.
- We know the number of elephants and lions in Africa. But we don't know the number of deafblind children. UNICEF has made a commitment on collecting and analyzing data become disability disaggregate in its commitment to the Global Disability Summit 2022.
- Enabling environment is the second point I want to cover, and this includes: policy, legislation, and institutional framework to include children with disabilities including those deafblind in development and humanitarian interventions. It is great to know how many they are and what is their situation. But it doesn't suffice.
- We need those enabling environments in place to hold duty bearers accountable.
- The third point is alliance. Disability inclusion requires multi-sectoral collaboration and can't be achieved in a silo. So, we need to build alliances/partnership and pursue the path of inclusion. We need more allies different from those before to realise the leave no one behind agenda. That is where the UN entities like UNICEF can work in alliance with persons with disabilities and their organizations to achieve an inclusive future.

- Last, but not least, the data acquired, the enabling environment created, and the alliance formed needs a clear financial commitment to deliver strong results.
- We realize a clear disconnect between policy aspirations and budgetary allocations. We need to bridge this gap and hold our governments accountable to budget for the inclusion of our deafblind members of the community.
- This budget can be used to overcome disability related costs including interpreters to facilitate their inclusion to education, employment, and any other aspects of life independently.
- UNICEF is preparing its first-ever disability inclusion policy and strategy (2022-2030) and the document recognizes the need to follow a twin-track approach towards reaching persons with disabilities. The DIPAS is believed to have a concrete accountability mechanism to track progress and ensure the allocation of required resources.

Deafblind Communication Challenge in Malawi

Ishmael Spriano

Secretary General, Visual Hearing Membership Association of Malawi (VIHEMA), Malawi

Muzza Owen Thole

Social Inclusion Officer - Kasungu Deafblind Initiative under VIHEMA Deafblind Malawi, Malawi

In Malawi, deafblindness persons experience deeper levels of discrimination compared to those with less complex disabilities. Their major challenges encompass communication and interacting with others as well as learning and mobility. This often leads to lifelong exclusion within their families and as community. VIHEMA Deafblind association in the country advocates for rights and needs of the said population. However, the interventions have encountered several challenges in improving the general welfare of families of persons with deaf blindness; as the association struggles financially to implement activities for the betterment of deafblind.

Negative attitude and lack of knowledge on deafblind management and communication among service providers including the society lead to the following problems among deafblind

Lack of proper access to Health services

Lack or poor communication between medical practitioners and deaf blind contributes towards deprivation of health fact file to put in writing while making medical prescriptions leading to prolonged illnesses, addition disability and in some cases death.

Safety

In most cases deafblind girls are rape victims when left at home without proper inspection. For example, Salima and Kasungu districts have recorded many cases of unplanned pregnancies and not knowing the persons impregnating them.

Psychological support

Depression amongst the deafblind is common with challenges emerging from communication. Failure sharing their problems with other family members is a concern. In the same, family members have no education or knowledge about deafblind communication and management. This means deaf blind are subjected to prolonged mind suppressions leading into depressions.

Conclusion & Recommendations

The conference shall meaningfully help to intensify their abilities, enabling them earn an income to support their families and building their capacity to advocate for their rights. Rapid response program could be initiated in combating safety livelihood of the deaf blind.

There is a need therefore for each family having a case of deaf blind sending one representative to obtain education on counselling and language technical-know how on deaf blind.

There is therefore a need to incorporate Deafblind communication in the health sector to easily comprehend with communication.

How an intervention on the Tactile Bodily Modality can -improve Communication: A Case Study of a Girl with Congenital Deafblindness in Zambia

Hellen Shakele
Faith Baptist School for the Deaf

Abstract

Deafblindness is a sensory disability which results from a combined visual and hearing impairment in an individual and its impact is manifested in the difficulties which persons with deafblindness experience in accessing information and the environment in which they live. The loss of sight and a sense of hearing entail resorting to tactile bodily communication in order to receive and send information for individuals with deafblindness. In Zambia, there are about least 2000 persons living with various levels of deafblindness and yet their existence is hardly known due to a very limited awareness and recognition of this disability

This study explored how an intervention in the bodily tactile communication can improve communication between a person with deafblindness and his/her communication partners with special focus on a child with congenital deafblindness and her family members in Zambia. The study took a qualitative case study approach which the participants included the child, her brother and her mother as well as the researcher who also acted as a role model in tactile communication and four members of the reflective team who provided insights in the video recordings of the communication episodes in the home. The partners' ability to communicate in the tactile bodily modality observed through feeding, bathing, self-dressing and playing activities.

Guided by the Diamond Model and the Dialogical Space Model of tactile bodily communication modality in children with congenital deafblindness, the study confirmed that providing tactile bodily communication intervention results in effective communication among children with congenital deafblindness.

In conclusion, the study observes that children with residual sight or hearing stand a better chance of developing effective tactile bodily communication than those without. However, this can only happen if they are exposed to tactile bodily communication at a very early stage of their life.

Keywords: Deafblindness, Congenital Reciprocation and Bodily tactile

Introduction

Persons with congenital deafblindness mainly communicate using the bodily tactile modality. Their expressive communication is often formulated by an authentic language that gives the person low readability toward the rest of the world.

This Study is motivated by the need for more knowledge about interventions that can contribute to solve the communication barriers between children with congenital deafblindness and other people in their respective home communities in Zambia. Janssen

and Rødbroe (2006) describe congenital deafblindness as a complex variation of deafblindness with onset before language acquisition. CDB hinders the development of a basic reciprocal and sharable communicative way of relating to the world through vision and/or hearing. Access to communication supported by the bodily tactile modality is especially important for children with congenital deafblindness as their potential for language learning is not likely to develop without such access (McInnes & Treffery, 1999; Foote, 2018, Forsgren, 2018).

This study approaches communication from a relational bodily-tactile point of view, in line with guidelines on congenital deafblindness and communication (Janssen 2003-1; Nafstad and Rødbroe, 2015), (2018). The sign locus can be located where the child felt the impression of an action, and a sign can be performed as perceived from a tactile perspective (Forsgren, 2018). The knowledge and competence which is required to develop communication from the already existing interaction is therefore more than tactile sign language and Zambian sign language. The communication partner must recognize how the child expresses experientially based highlights and be able to map tactile sign language on to the child's gestural expressions (Souriau, 2015; Foote 2018) to explore if an intervention with a role model who demonstrates communication in the bodily tactile modality and builds on knowledge and competence on sign language can improve the communication between a child with CDB and her mother and brother

Literature and Theoretical Framework

Congenital Deafblindness in Relation to Communication Development and the Bodily Tactile Modality

The bodily-tactile modality can be non-impaired in children with CDB. The bodily tactile modality can support or compensate impaired distal senses in basic communicative interaction such as turn-taking, reciprocation and imitation of actions, signs and conversational roles, and in directing, following and sharing attention (Janssen and Rodbroe 2007; Nafstad and Daelman, 2017). The bodily-tactile modality can also be used to develop or support deictic pointing (Souriau 2015), stay in conversational contact, negotiate sharable tactile signs that come from the child's own gestures (Godø 2018; Forsgren 2018) and give perceptual access to conventional signs and culture (Gregersen 2017).

Bodily-Tactile Communication Practices

An important issue in bodily-tactile communication is how hands are connected. The hand-over-hand and hand-under-hand positions allow the partner to share attention with the child without forcing or directing his movements (Miles 1999; Janssen and Rodbroe, 2007). Once the communication partner and a child are focused on the same element, the partner can help the child explore and expand the shared focus of attention and expand shared concepts. Hand-over-hand means that the hand of one partner is relating by a light touch to the relating hand of the other partner. The mother's hand may when lightly placed on top of the child's hand feel if the child lets her demonstrate to the child the performance of an action or a sign. The mother may also place her hand under the child's hand to let the child follow the direction of her attention to something she wants to show or share, and in this

manner guide exploration of objects and participation in activities.

Hand-over-hand and hand-under-hand is also used to describe the hand positions of the child and the partners in their conversational interaction. Shifts between conversational hand positions signal turn-taking and shifts between listening and talking. Reciprocity in conversation means that the child can 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. There can also be reciprocity in social interaction through imitation (Hart, 2006).

Objects of reference are objects that refer to other objects, activities, places or people. A cup can represent at the activity of having a drink. According to Kathleen and Fiona (2009) objects of reference may be a bridge into communicative interaction and support understanding of the environment. Tangible objects of reference can be combined with sign language (Blaha1999). Several recent studies have demonstrated that sign language can enhance communication with persons with CDB but it requires adaptations to the bodily tactile modality and to the conceptual world of the individual child. Iconic and deictic aspects of signed communication are foregrounded.

Methodology

Research Design

This is a qualitative single case study design which enables close analysis of the interaction between a small number of participants (Cohen and Manion, 2017). The design allows the researcher to have a richer understanding of the interaction that is taking place between a child and her most important communication partners in daily life, and gives an opportunity for empowering the interaction in its naturalistic setting. The use of sharable bodily-tactile aspects in communication between mother-child and brother-child in interactive routine situations are videotaped and analyzed before and after an intervention that aims to empower the existing communication. The intervention involves the researcher as a role model for the mother and brother demonstrating sharable aspects of bodily tactile communication with the child. The transcribed result of interaction-analysis is used as material to answer the research questions.

Participants

The participants in this research included a three-year-old girl with CDB, her 17-year-old brother and her mother. The other participants were researcher and four members of the reflective team. The child in this study is a three-year-old girl who was born with congenital deafness, and her vision is severely impaired due to bilateral cataracts. She uses residual functional vision to orient herself in the well-known environment inside the house and outside. The Mother is a primary school teacher in her 40s. She does not know ZSL but uses objects of reference for example spoon to communicate eating time and cup for drink and she uses vocal expression to communicate with her children as well as adaptive sign.

The Brother of the child

The brother who participates in the study is a 17-year-old boy with combined visual and hearing impairment, born deaf with partial vision and doing Grade seven at a special school for the deaf.

The Reflective Team members

A reflective team consists of professionals with practical experience in a particular topic. Its purpose is to make practitioners reflect over the knowledge and experiences by listening and commenting on the interview in a research (Kjaer&Tulinus, 2003). The role of the reflective team members was to provide a rich analysis of the videotaped interaction during and after intervention based on the practical experience of deafblindness and bodily tactile communication.

The Research Setting

The research took place in the home environment of the child. The home is located in one of the low-income suburbs in Lusaka, the largest city in Zambia. The research involved observing how the child communicates regularly with her mother and her brother during bathing, feeding, self-dressing and playing as described below

Bathing

Bathing includes contact with a large dish of cold or warm water in which the child sits. The mother leads the child into the bathing process which involves rubbing a tablet of the soap on the child's body after splashing water on her body. The mother also dries the child's body with a bath towel before assisting her to wear clean clothes.

Feeding

The feeding includes access to kitchen utensils namely plates, a cup and a spoon. The regular breakfast food is porridge, bread and tea with sugar. The usual food for lunch and supper is nshima, the staple food in Zambia which is thick corn meal porridge accompanied by relish which is usually beans, meat, soup, fish and vegetable mainly rape. The child sits on a mat which is spread on the floor during meals and is assisted to locate the dishes by the mother or the brother who brings the food to the child.

Intervention

After observing the above situations, the role model/researcher selected 1 recording to help determine the child's expressions of focus, interest and aspects of communication that requires more or less intervention. Based on these observations, the role model introduced new knowledge on bodily tactile signs to the child, mother and brother. The main focus for intervention was to build on the already existing sign language, bodily tactile gestures used by the partners and to teach the child how to communicate in the different daily situations of feeding, bathing, self-dressing and playing. The researcher demonstrated bodily tactile

signs, to the child, mother and brother how to effectively communicate with the child with CDB. The intervention was performed according the following steps.

Data Collection

The researcher made 4 video recordings of the child interacting with her mother and her brother before intervention and 4 video recordings after intervention on bathing, feeding, self-dressing and playing.

Video recordings and selection. The researcher made another two video recordings of the child interacting with researcher as a role model in bathing and playing activities during intervention. Also, two extra video recordings of mother-child interaction and brother-child interaction were made during intervention and one video was recorded during intervention where the researcher as role model was demonstrating with the congenital deafblind child during bathing.

Data analyses

Children with congenital deafblindness learn communication through social interactions and reciprocations. The analyses were guided by the Diamond model (Nafstad & Rodbroe, 2015) which describes the social interaction and reciprocity in the interactions and the Dialogical Space model which helps to analyze attention directing and attention following gestures and postures that occur within the tactile conversational frames (Nafstad, 2018). The researcher used the following categories in analyzing each transcript: a) communication aspects, b) partner's communication, c) child's communication, d) interactional elements according the Diamond model, and e) dialogical elements according the Dialogical Space model, f) agreement by the reflective team. In the last category the main aspects of special interest on which the team agreed in consensus were described. After analyzing all the transcripts, the researcher made comparisons between the baseline results and the intervention results across the four situations

RESULTS

Results are presented according to the themes from the research questions and the themes from the two analytical models which means that for every observed interaction situation aspect of interest are described before and after intervention regarding the themes: a) communication aspects') partner's communication) Child's communication) interactional elements) Dialogical elements) agreement reflective team.

Feeding

Feeding before Intervention

The Communication aspects: The mother was acting throughout the activity but brother signed EAT and was pointing once. There was no real interaction, as the child was left alone and no one to interact with. The mother was acting most of the time e.g. by washing the hands of the child, by lifting her up, moving the chair, pushing the plate without

communication to the child. At the end of the activity brother signed EAT pointed and grabbed hands of the child by force. The child's communication: child was looking to the mother now and then, pushed an object away because there was no real interaction. The partners addressed the girl by acting most of the time and furthermore by physical contact, and by speaking and listening. The reflective team agreed that there was no face to face interaction with the mother, but some interaction with the brother in pushing away the plate. The child lacked the experience of being together in the shared here and now.

Feeding after Intervention

The Communication aspects by the mother observed in the data were ZSL; hand over hand contact, pointing gesture, tapping the child before communicating. There was frequent use of ZSL by the mother e.g. she signed by placing her fingers on her mouth and signed 'TIME TO SIT' by placing two right fingers on her two left fingers. She also signed EAT now in ZSL by putting her hand on the mouth. In the transcribed material there was an example of hand over hand contact about how the mother and the child used a hand position to make a sign for touching the food together. The mother also used a pointing gesture after tapping the child and pointed to the place where the food was and after that the child got the food. The mother tapped to attract attention of the child, by touching the head. Mother used ZSL as she pointed her wrist to indicate TIME. The mother used tapping gestures most of the time to direct and attract the child's attention. She called the child with her fingers visually and pointed to the plate of food for indicating EAT now.

Child's communication was mainly looking to the mother and joining in the acting together. The child reacted on the tapping gestures by turning and nodding her head. She gave attention to the mother by reacting on the signs and imitated by pointing. There was face to face interaction throughout in the activity when mother was sitting in front of the child when she was eating. There was body to body interaction when mother was helping the child to wash her hands, their bodies were in physical contact. The reflective team agreed that during interaction mother and child took turns, in developing and understanding the communicative expression in a meaningful manner.

Pictures to illustrate some important interaction patterns



Picture: Example of hand over hand positioning



Picture: Example of reciprocation

Conclusion and Discussions

In this section the research questions will be answered, the results will be linked to the

literature and the theoretical framework. There were also several limitations in this study which will be described and finally recommendations for future research and practice will be given:

Sub-question 1." What kinds of communication aspects (such as bodily tactile gestures, signs, language, vocal expressions, and interactional elements) are used in daily life situations in mother-child and brother-child communication before intervention?" Before intervention in all activities the mother and the brother led mostly the actions and the child followed most of the time and joined in. The mother used also vocalizations. The brother used some Zambian Sign Language tapping gestures to get the attention of the girl and some pointing gestures. He showed reciprocity once, and hand over hand positioning during play.

Sub-question 2. "In what way does the intervention have an effect upon bodily tactile aspects of partner's communication?" The intervention existed of a role model approach in five steps in which the role model demonstrated aspects of tactile bodily communication and in which she gave video feedback, among other steps. After intervention both partners used ZSL, objects of reference, imitation, gestures, hand over hand positions to communicate with the child throughout the activities. The partners were aware of the child's signals and interpreting them with insight and thoughtfulness by responding in an accurate manner

Sub-question 3, In what ways does the intervention have an effect upon the child's communication?'

The intervention had a positive effect on the child's communication with the partners. She showed many more communication aspects in the bodily tactile modality after intervention, such as imitation, pointing, gestures, hand over hand positions, ZSL signs and object of reference. She initiated acts in a body contact during play. It can be concluded that the intervention had indeed a positive effect on a variety of bodily tactile communication aspects between the child and her family communication partners. The most important aspects which improved were the use of hand over hand positioning, the use of tactile gestures, and tangible object of reference, and ZSL signs, reciprocity, body to body interaction.

The finding in this study clarifies how use of sign language and hand positions can benefit persons with CDB to improve their communication. The study has shown how competent mother and brother were communicating with the child after intervention using ZSL, Imitation and hand positions. The utterances that were addressed by the child to the partners in a gestural expression were answered by the partners. Lastly it has shown the need to focus on whole body communication, understanding and relating to communicative expressions.

Results related to theoretical background and critical reflection

The Diamond Model (Nafstad&Rodbroe, 2015) helped establish that the three most basic environmental relations in face-to face interaction; attachment, social- interactive play and exploration were already in place in mother-child and brother-child before intervention. Intervention could focus on the more complex relation "Conversational interaction". This

relation requires interaction patterns that enable mutual attention and reciprocation of roles and perspectives in relation to actions, signs and utterances. The child in the study had residual vision, and the study exemplifies the need to think about bodily- tactile support in communication development even for a child who has residual vision.

The study showed that residual vision has been sufficient to help the girl be aware of the world beyond her reach. She looks at others' activities, at places, sometimes at persons/faces. This awareness of course is a very strong motivating force. However, the child showed that she profits immediately from the bodily-tactile support. Therefore, the study confirms the relevance of relating to theory about bodily gestures, hand-over-hand positioning and body-with-body interaction. In literature it was stated that for children with CDB it is important that partners not only use face to face interaction but also body to body interaction. Body to body interaction can combine the child's need for togetherness and secure base which are essential for growing to independence and self (Gregersen, 2018). The hand over hand positioning is important for giving the child the opportunity to explore without being forced or directed too much (Miles, 1999). In this case we saw fluent hand over hand contact throughout the different activities after intervention; while before intervention it was observed at several moments that the bodily tactile interaction was forced or more directive.

The results of this study showed that to work with persons with CDB, there is need for communication partners to be fluent signers. It is important for all communication partners of persons with CDB to receive guidance in signing, so the person with CDB has access to language (Ask, Larsen, 2016). But this study showed at the same time that only sign language is not enough. There must be a connectedness between signing and adapted interaction patterns. The role model approach that was used in this study enabled mother and brother and child to learn through reciprocation of roles and imitation. It is a natural form of learning which does not necessarily require shared reference to theoretical concepts. Immediate results that find the right communication modalities and forms for the child are very important in early communication intervention (Chen, 2005).

In this study the role model was also a mother of a child with CDB. For the mother and brother to feel competent, it was important that the relation to the role model is sufficiently symmetrical. Without sufficient identification it may not work. This role model approach is therefore different from demonstrations by a competent professional about how to do things. This might have the opposite effect. The role model approach may have particular relevance in the African context, where woman- to-woman and mother-to- mother support are used as resources also in other fields (Erwin, et al., 1992; Crawford & Smith, 2005).

Limitations of the study

First it is not possible to generalize how the bodily tactile modality can improve communication from only this qualitative single case study. It would take more case studies to find out if the results of this role model approach are successful for more children. In this case a child with More interventions with the same approach by different role models must be applied.

Recommendations for future research and practice

It is recommended that more case studies with this role model approach will be applied to more children with CDB, and to more children with other variations of CDB, not only children with residual hearing and vision. It is recommended that this role model approach will be applied also to more children with other disabilities such as multiple sensory disabilities. It would be very interesting to investigate if this specific role model approach in which a mother guides another mother, or a parent guides another parent, can be implemented in Western countries not only in deafblind education but in early intervention in general.

References

- Blaha, R (1999). Calendars for students with multiple impairments including deafblindness: A systematic process supporting communication, time, and emotional being. Austin, Texas: Texas School for the Blind and Visually Impaired Outreach Department.
- Cohen, L., Manion, L., & Morrison, K. (2018). *Research Methods in Education*. (8th Ed.). London
- Erwin, D. O., Spatz, T. S., & Turturro, C. L. (1992). Development of an African-American role model intervention to increase breast self-examination and mammography. *Journal of Cancer Education*, 7(4), 311–319.
<https://doi.org/10.1080/08858199209528188>
- Gregersen, A (2018). Body with Body: Interaction with children in the human niche. *Journal of Deafblind studies on Communication*. Vol. 4, 2018, pp. 67-83
- Flick, U., (2014). *An introduction to qualitative research*. SAGE publication.
- Janssen, M. & Rødbroe, I. (2006). *Communication and Congenital Deafblindness: Congenital Deafblindness and the Core Principles of Intervention*. VCDBF/ Vitaal. The Netherlands.
- Relations. Intervention Communication with Congenital Deafblindness, Materialecentret. Kollegievej.*
- Nafstad, A. V. & Rødbroe, I. B. (2015). Communicative relations: interventions that create communication with persons with congenital deafblindness. Aalborg: Materialcentret.

Where do we Start?

Musabyimana Joseph

Executive Secretary, Rwanda Organization of Persons with Deaf-Blindness (ROPDB)

Furaha Jean Marie

President, Rwanda Organization of Persons with Deaf-Blindness (ROPDB)

In Rwanda from National census of 2012 we are counting 450,000 people with disabilities from different categories of disabilities, a total number of people who are Deaf-Blind is not known and Deaf-Blindness is not recognized as a distinct disability category, during the categorization Deaf blind were put in an ambiguous category were not known by the whole community. ROPDB has mandate to strengthen the voice of Persons with Deaf-Blindness in Rwanda.

Background of DeafBlindness in Rwanda

It started in 2011 as the Rwanda union of the blind project .before being the project, the Executive Director of Rwanda Union of the Blind Dr.Donathilla KANIMBA with her team were in the training for three weeks in Sweden and they published the announcement on Stockholm TV to support that project; Swedish federation of Deaf-Blind (FSDB) through the partnership with My Right (umbrella of organizations with supported the project from phase one in 2011 until phase three by the end of 2018, In 2018 the project became Organization, In 2018 ROPDB elected different committee in the organization to govern it finally RODB did outreach visit in 3 working districts to identify persons who are Deaf-Blind.

Key achievements

With the support of FSDB (Swedish Federation of Deaf-Blind), My Right and Disability funds (DRF); ROPDB got a Legal personality as a local NGO, ROPDB conducted advocacy in different government institutions (Decision makers), Organization has official documents, Organization becomes a member of World Federation of Deaf-Blind, Deaf-Blind international, ROPDB is a member of National Union of Disability Organization in Rwanda(NUDOR), Organization has 3 staff 1 cleaner and 1 guard, Identified more than 300 members in 5 districts, Operating well in independent office, trained 21 tactile sign language interpreters to break communication barriers between deaf-blind persons and community, ROPDB also trained family members about home communication signs, two of board member trained about braille writing for 9 months.

Findings from the Outreach done

From Outreach work carried out in 2018 from 3 districts out of 30 of Rwanda, 167 deaf-blind persons have been identified while detail was patchy, From 167 identified 60%are children and 40 are Adults, The majority are children between 2 and 18 years, while there were some adults between the ages of 50 and above, No children were found in education and no adults employed. Some have additional disabilities. , Community understanding and attitudes were generally poor, regarding them with pity and to be kept out of sight and

there was no official government policy towards deaf-blind persons or recognition of Deaf blindness as a specific category of disability.

The main purpose of this Abstract

This Abstract will help to: Advocate for government to recognize persons with Deaf-Blindness in their programs and policy change, reach the unreached Deaf-Blind persons in their respective communities, Advocate for them to be included in different supportive government programs, increase their visibility and find a sustainable solution to their concern, Have real numbers (data) of persons with Deaf-Blindness in Rwanda, Identify their challenges and propose sustainable solutions and Engage partners to support persons with Deaf-Blindness in Rwanda Technically and financially.

Future Projection of ROPDB

ROPDB is Planning to network with many partners to sustain itself because it needs more support in; communication, education, health, and socio-economic development, In Health domain there is too much support needed because deaf-blindness develops other physical disabilities, we are planning to advocate for their families to get financial support, conduct meeting and conference with decision and policymakers, Increase the visibility of Deaf-Blindness in the community, strive for the education of children who are deaf-blind, increase the participation of persons who are Deaf blind in the community, increase awareness campaign in the community.

Visual Functioning among Learners with Hearing Impairment in Schools for the Deaf in Ghana:

Dr Michael Agyemang Kwarteng; Prof. Khathutshelo Percy Mashige; Dr Daniel Sunkwa Quarcoo Dogbe; Dr Samuel Kyei; Mrs Pirindhavellie Govender-Poonsamy.

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 Jamasi 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.

Keywords: Visual impairment, dual sensory loss, School for the Deaf, hearing impairment

INTRODUCTION

Most 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). Because 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, & Tyghsen, 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 Ovenseri-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, since 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 Ovenseri-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 Ovenseri-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 Ovenseri-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.

Funding: This study was funded by the African Researchers' Initiative (ARI) research grant, Deafblind International (DbI), Switzerland.

Affiliation(s)

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.

Department of Special Education, Faculty of Education, University of Winneba, Winneba, Ghana.

Department of Optometry and Vision Science, School of Allied Health Sciences, College of Health and Allied Sciences, University of Cape Coast, Cape Coast, Ghana

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., McAvinchey, A., & Ryan, B. (2014). Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. *Arch Dis Child*, 500-50

LAUNCH OF THE DBI AFRICAN NETWORK

During this 1ST Dbl Africa Conference on Deafblindness we have seen the need to establish a Network whose aims are to:

- Sustain the gains made from this 1st Africa Conference on Deafblindness
- Strengthen collaboration with the existing Dbl Networks
- Champion and advance deafblindness in Africa (Education, awareness, socio-economic empowerment, research, technology, early Identification)

Dbl Africa Network

There are 4 Sub regions of Africa that are interconnected

- Eastern Africa Region
- Western Africa Region
- Southern Africa Region
- Northern Africa Region

There are 3 Priorities

- Early identification
- Technology
- Research

Terms of reference and operational framework shall be developed to guide Dbl African Network Activities:

- “Let us uphold the bonds that frame our destiny”
- From Nairobi the Green City in the Sun
- May 2022

REPORT ON EXCURSION SPONSORED BY THE DBI OUTDOOR NETWORK

Introduction

A team of 12 participants at the DBI Africa Conference and their assistants participated in the excursion sponsored by the DBI Outdoor Network on 15th May 2022. The team consisted of 5 deafblind participants, 2 blind participants, 1 deaf participant and 4 sighted assistants. The team consisted of Kenyan, Ugandan and Zimbabwean citizens. Several other participants had wished to participate but their travel bookings could not allow them. The excursion, which aimed at giving the participants a close interaction with nature and other tourist attractions, consisted of three main attraction sites: the National Museums of Kenya, the Nairobi National Park and the Giraffe Centre.

Attraction Sites

National Museums of Kenya: Here the participants interacted with a wide range of archeological, historical, cultural and wildlife information and artefacts. With the assistance of an experienced guide, the participants visited a selection of galleries, including the Early Man archeological artifacts and excavations, the History of Kenya gallery, and the Peoples of Kenya cultural gallery. They also visited the Birds of Kenya and the Snake Park.

Nairobi National Park: At the National Park, the Game Wardens assisted the participants to feel a stuffed Lioness and a stuffed Cheetah. In addition, the participants were entertained by Maasai dancers and also got a chance to interact with them and feel their attire and cultural weapons. It was not only a learning experience for them but also for the dancers who got a chance to interact with deafblind people and learn more about deafblindness.

Giraffe Centre: At the Giraffe Centre, the participants had an exciting opportunity to touch and feed live giraffes. After, they sat down for a lecture on giraffes and a feel of the various bones of giraffes. The professional warden at the Centre provided the participants ample time to each feed the giraffes and to ask questions regarding giraffe life and anatomy.

Conclusion

From the excitement and feedback from the participants, the excursion was a great success. It provided them with an outdoor experience that they had never before experienced. They requested for their expressions of gratitude to be conveyed to the sponsors and consented to their photos and videos to be used by Deafblind International.

Excursion Photos



National Museums of Kenya
Learning about the Birds of Kenya



National Museums of Kenya
Learning about Kenyan Cultural
Artefacts



National Museums of Kenya
Learning about Fossils of Early
Man



Nairobi National Park
Learning about the Big Cats



Nairobi National Park
Learning about Maasai Dress and
Culture



Nairobi National Park
Posing for a Photo after an
Exciting Visit



Giraffe Centre
Feeding the Giraffes



Giraffe Centre
Learning about Giraffe Anatomy



Giraffe Centre
Posing for a Final Photo!

CONFERENCE RESOLUTION

We, the participants at the Deafblind International 1st Africa Conference on deafblindness held in Nairobi and online from 12th to 14th May 2022, representing more than 35 countries,

AFFIRMING the fundamental rights and freedoms of all persons as enshrined in the charters of the United Nations and the African Union;

RECOGNIZING the rights and freedoms of persons with disabilities as expounded in the United Nations Convention on the Rights of Persons with Disabilities and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa;

CONCERNED that deafblindness remains an obscure and unrecognized as a distinct and unique disability in many African States;

APPALLED by the continued denial of the rights and freedoms of deafblind persons in Africa, particularly in the areas of health, education and social inclusion;

AWARE of the challenges faced by families in Africa while bringing up their children who are deafblind;

CONCERNED, further, of the low level of knowledge, research and evidence on deafblindness in Africa;

RECALLING the principles of the Sustainable Development Goals to leave no one behind and to reach those furthest behind first;

Therefore, resolve to:

1. Strengthen our collaboration in promoting the rights of persons who are deafblind in Africa;
2. Promote the DBI Africa Network as a platform for sensitization and exchange of information, knowledge and expertise on deafblindness in Africa;
3. Continue awareness creation, collaboration and exchange of knowledge through the convening of a 2nd DBI Africa Conference within the next four years.

We further call upon:

1. African Governments to:

- a. Institute legislative measures to recognize deafblindness as a unique and distinct disability;

- b. Strengthen early identification, intervention and referral of children with deafblindness at the community level;
- c. Implement social protection and other programs to ease the burden of care for families of children with deafblindness;
- d. Design and implement educational and training programs suitable for persons who are deafblind to enable them transition into the world of work;
- e. Ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, the United Nations Convention on the Rights of Persons with Disabilities, and other regional and international instruments that promote the rights of persons who are deafblind;

2. Institutions of higher learning in Africa to:

- a. Create opportunities for admission and pursuit of higher education by persons who are deafblind;
- b. Expand teacher training and other specialist programs in the area of deafblindness;
- c. Promote research, knowledge creation and dissemination in the field of deafblindness;

3. Development agencies and service providers to:

- a. Increase investment in programs for deafblind persons in Africa, with particular focus on countries where deafblind services are furthest behind;
- b. Promote inter-agency and inter-sectoral collaboration in the provision of services to persons who are deafblind;
- c. Undertake action research to enhance the relevance of programs and services for persons who are deafblind;
- d. Include persons who are deafblind and their families in the design, implementation and evaluation of programs and services.

- END -