

# *An Examination of the Support Systems Available for Children in Early Childhood who are deaf-blind in Zambia.*

Agnes Mando Banda-Zambia Open University  
Daniel Lupiya Mpolomoka-UNICAF  
Rose Chikopela- Chalimbana University  
Brian Mumba-University of Lusaka





# PRESENTATION OUTLINE

- Introduction
- Research objectives
- Research questions
- Literature review
- Methodology
- Findings
- Recommendation



# INTRODUCTION

- Deaf-blindness is a rare condition in which an individual has combined hearing and vision loss, thus limiting access to both auditory and visual information.
- For child who is deaf-blind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach.
- Such children are effectively alone if no one is touching them.

# DEFINITIONS: HICHCY

- According to the National Dissemination Centre for Children with Disabilities (NICHCY),
  - deaf-blindness does not necessarily mean complete losses.
  - The word deaf-blindness may seem as if a person cannot hear or see at all.
  - The terms actually describes a person who has some degree of loss in both vision and hearing.
  - The amount of loss in either vision or hearing will vary from person to person.

# Percentage of DeafBlind Children who have Additional Disabilities

ADDITIONAL DISABILITIES	% OF CHILDREN
Cognitive	64
Physical	58
Complex health care needs	51
Behavioral	9
Other	19
One or more additional disabilities	87



# CAUSES OF DEAF-BLINDNESS

- There are many causes of deaf-blindness.
- Those that are present or occur around the time a child is born include prematurity, childbirth complications, and numerous congenital syndromes, many of which are quite rare.
- Deaf-blindness may also occur later in childhood or during adulthood due to causes such as meningitis, brain injury, or inherited conditions.
- It is not uncommon for the same conditions that cause deaf-blindness to also lead to additional cognitive, physical, or other disabilities and health care needs.



# Most Common Causes

- The most common causes of deaf-blindness in children are:
- **Complications of Prematurity**
- **Hereditary Syndromes/Disorders**
  - Examples:
    - **CHARGE Syndrome**
    - **Usher syndrome**
    - **Down syndrome (Trisomy 21 syndrome)**
- **Prenatal complications**
- Examples:
  - **Cytomegalovirus**
  - **Hydrocephaly**
  - **Microcephaly**
- **Postnatal complications**
- Examples:
  - **Asphyxia**
  - **Severe Head Injury**
  - **Meningitis**



- The children's concepts of the world depend upon what or whom they have had the opportunity to physically contact.
- Children who are called deaf-blind are singled out educationally because impairments of sight and hearing require thoughtful and unique educational approaches in order to ensure that children with this disability have the opportunity to reach their full potential.
- There is paucity of studies of these children in Zambia.



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# OBJECTIVES

- a) To establish the support systems that are available for deafblind pre-schoolers in homes.
- b) To establish support system available for deafblind children in pre-schools
- d) To examine support systems available for parents and caregivers of deafblind children.



# RESEARCH QUESTIONS

- a) What support systems are available for deafblind pre-schoolers in homes?
- b) What support system are available for deafblind children in pre-schools?
- d) What support systems are available for parents and caregivers of deafblind children?



## LITERATURE REVIEW

Research in the field of deafblindness is limited (Dammeyer 2014, Danermark/Moller 2008) and is further limited in the context of Zambian with deafblindness.

**Anthony, T. L. (2016).** Early Identification of Infants and Toddlers With Deafblindness. *American Annals of the Deaf*, 161(4), 412-423.  
doi:10.1353/aad.2016.0034

**Bruce, S., & Bashinski, S. (2016).** Individualizing and Personalizing Communication and Literacy Instruction for Children who are Deafblind [Abstract]. *Journal of Deafblind Studies on Communication*, 2.  
<http://jdbssc.rug.nl/article/view/25421>.

**Bruce, S. M., Nelson, C., Perez, A., Stutzman, B., & Barnhill, B. A. (2016).** The State of Research on Communication and Literacy in Deafblindness. Retrieved September 29, 2020, from <https://doi.org/10.1353/aad.2016.0035>.

**Dammeyer, J., & Larsen, F.A. (2016).** Communication and language profiles of children with congenital deafblindness. *The British Journal of Visual Impairment*, 34, 214 – 224.



# Literature Cont'd...

- **Epstein, J. (2018).** School, family, and Community partnerships: preparing educators.  
<https://www.taylorfrancis.com/books/mono/10.4324/9780429494673/school-family-community-partnerships-joyce-epstein>
- **Hart, P. (2006).** Using imitation for congenitally Deafblind Adults: Establishing communication partnerships. *Infant and Child Development.*
- **Mwewa, K. M. and Simalalo, M. (2020).** Challenges of family involvement in the education of learners with deafblindness in selected special schools of Southern Province of Zambia, Lusaka: *Interdisciplinary Journal of Education.* Volume 1, № 1
- **Rönnberg, J. and Borg, E. (2001).** A review and evaluation of research on the deafblind from perceptual, communicative, social, and rehabilitative perspective. *Scandinavian Audiology PubMed (2001)*



# METHODOLOGY

- The study adopted a mixed methodology and a descriptive research design.
- The population of the study comprised of
  1. Special education teachers,
  2. ECE teachers
  3. Head teachers
  4. District Education Board Secretary for Lusaka,
  5. Parents,
  6. Officers from the Deaf Association of Zambia and
  7. The Association for the blind.



# METHODOLOGY

## Data collection instruments

1. Questionnaires for teachers
2. In-depth interviews for head teachers
3. Focus group discussions with parents and caregivers
4. Key Informant Interviews for Associations focal persons and District Education Board Secretary

## Data Analysis

- SPSS version 25 analysis software was used for quantitative data
- Thematic approach was used for analysing qualitative data

# FINDINGS.....1

- Results reveal that there are no support systems for deafblind children available in ECE centres in Zambia.
- Deaf-blind children are not in pre-schools
- ECE Teachers have no knowledge or skills to handle deafblind children.

## FINDINGS.....2

- Parents and caregivers have nowhere to go seek assistance for communicating/and or teaching deafblind pre-schoolers
- There are no resource centres for borrowing books or materials that can aid in improving communication and mobility for deaf-blind ECE learners and teachers
- Materials and equipment like braille, white canes are not available for pre-school deafblind children



## FINDINGS.....3

- ECE centers have no sensory channels available for learning to enable deafblind children go through an individualized programme.
- Teachers and other stakeholders contended that sensory channels help children individually address their interests and unique ways of learning.

## FINDINGS.....4

- Assessment is crucial every step of the way.
- NO WONDER Miles (2008) posits that sensory deficits can easily mislead even experienced educators into underestimating (or occasionally overestimating) intelligence and constructing inappropriate programmes.

## FINDINGS.....5

- Unanimously, respondents acknowledged that it is important for children with deaf-blindness to be identified early in life when the brain is most sensitive to learning and begin receiving appropriate intervention as infants and toddlers.

## FINDINGS.....6

- Findings further reveal that there are NO NGOs, funded projects and or individual pressure groups that support and promote children and ECE learners in centres sampled.

# FINDINGS.....7

- Findings point to the many hiccups deaf-blind children and ECE learners face in pre-schools and in communities.
- For example, all respondents pointed out the limited access to information to support their daily living, communicate, and interaction with others.



## CONCLUSION

- There are no support systems put in place for deafblind children and their families.
- There is also very little awareness about this condition and the needs of deafblind children.
- The ECE teacher education curriculum omits this group of children and thus teachers expressed ignorance about their existence and how to handle them in a pre-school setting.
- There are no Early Intervention programmes for deafblind children in Zambia.



# RECOMMENDATIONS

1. The Ministry of Education and Schools should put in place support systems for deaf-blind ECE learners.
2. The Government and pre-schools should design sensitization programmes and training for families and educators regarding the assessment and education of infants and pre-school children who are deaf-blind.
3. There is need to put in place a multi-disciplinary team to work with parents and families in order to facilitate early Intervention.
4. The Ministry should set up a resource centre for parents, ECE teachers and deafblind children.

# REFERENCES

- Anthony, T. L. (2016). Early Identification of Infants and Toddlers With Deafblindness. *American Annals of the Deaf*, 161(4), 412-423. doi:10.1353/aad.2016.0034
- Bruce, S., & Bashinski, S. (2016). Individualizing and Personalizing Communication and Literacy Instruction for Children who are Deafblind [Abstract]. *Journal of Deafblind Studies on Communication*, 2. <http://jdbosc.rug.nl/article/view/25421>.
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- Dammeyer, J., & Larsen, F.A. (2016). Communication and language profiles of children with congenital deafblindness. *The British Journal of Visual Impairment*, 34, 214 – 224.



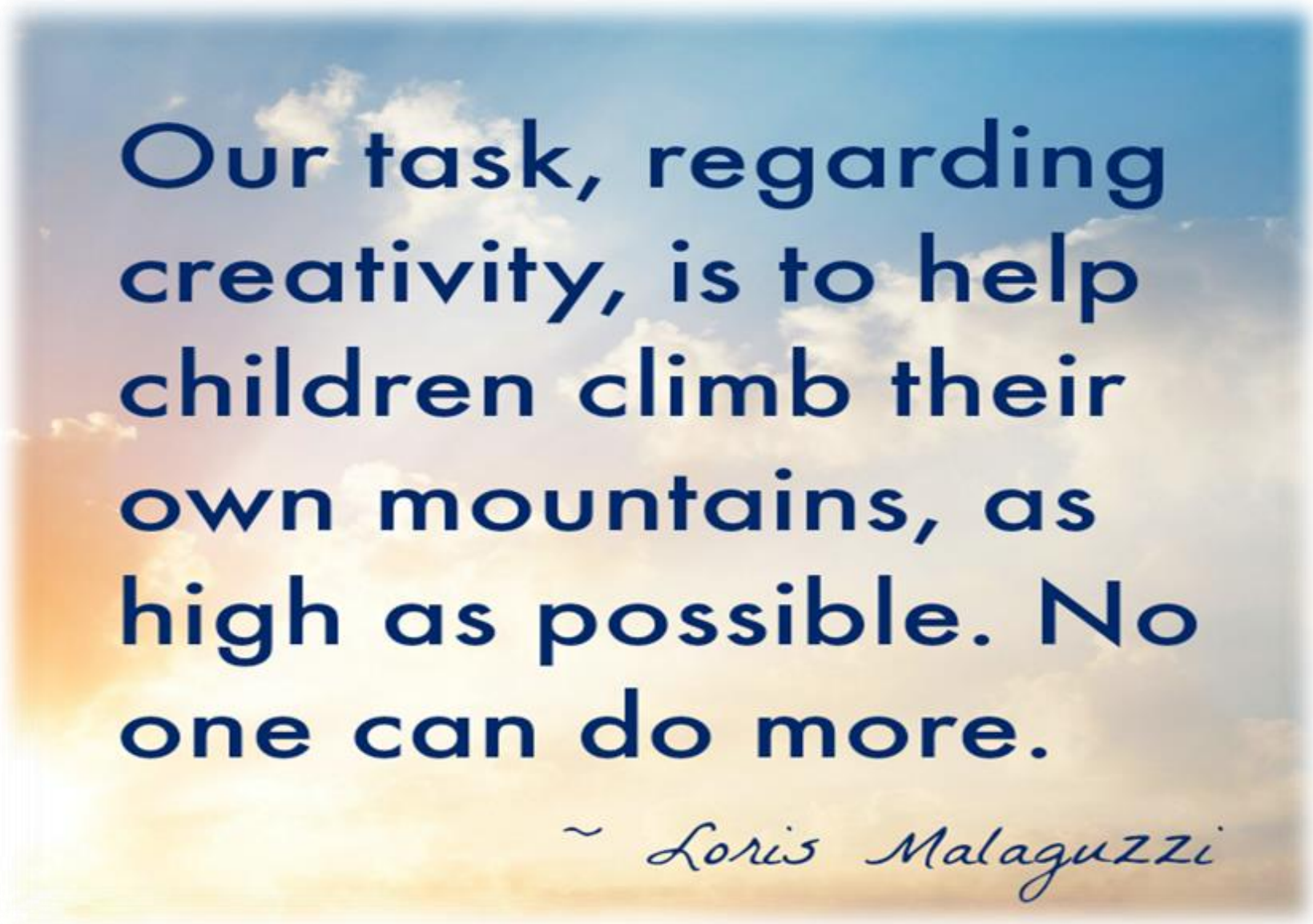


## References Cont'd...

- Epstein, J. (2018). School, family, and Community partnerships: preparing educators.  
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**THANK YOU FOR YOUR ATTENTION**

A rectangular background image showing a sunset or sunrise sky with soft, white clouds and a warm orange glow at the bottom.

**Our task, regarding  
creativity, is to help  
children climb their  
own mountains, as  
high as possible. No  
one can do more.**

*~ Loris Malaguzzi*