Assistant Writer in Examinations: Lived Experiences of Students with Deafblindness

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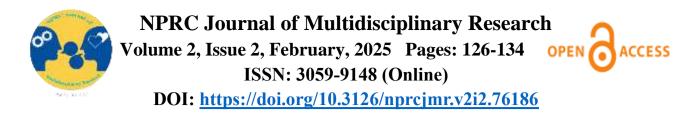
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Abstract

Background: Students with deafblindness face significant educational challenges, including a lack of accessible learning materials and discriminatory assessment practices. These barriers prevent them from fully exercising their educational rights, revealing a gap between inclusive education policies and their practical implementation. Despite constitutional mandates and international agreements advocating for inclusive education, marginalized students with disabilities continue to experience systemic neglect. **Objective:** This study aims to explore the lived experiences of students with deafblindness in educational settings, focusing on the challenges they face in accessing learning materials, participating in assessments, and receiving institutional support. **Methods:** A phenomenological research approach was used to capture the firsthand experiences of students with deafblindness. Data was collected through semi-structured interviews with three participants, allowing for an in-depth understanding of their educational struggles and the systemic barriers they encounter. **Findings:** The study reveals that students with deafblindness frequently experience marginalization due to inadequate support for braille literacy from government officials. Additionally, the lack of accessible

assessment accommodations places an undue burden on these students, further limiting their educational opportunities. Participants stressed the need for government institutions to take active measures to fulfill constitutional and international commitments to inclusive education. **Conclusion:** The findings highlight the urgent need for systemic reforms to ensure that inclusive education policies translate into meaningful support for students with deafblindness. Strengthening accessibility measures, improving braille literacy support, and adapting assessment practices are essential steps toward reducing educational disparities. **Novelty:** This study provides a critical examination of the disconnection between inclusive education policies and their real-world implementation, emphasizing the specific struggles of students with deafblindness. By centering their lived experiences, the research offers valuable insights into the urgent reforms needed to create a truly inclusive educational system.

Keywords: Deafblindness, marginalization, insufficient, policy, practice, inclusive education

Introduction

Deafblindness is a relatively novel concern within the context of Nepal, with limited awareness beyond organizations dedicated to persons with disabilities. Educational institutions, unfortunately, remain largely uninformed about the unique challenges and obstacles faced by students with deafblindness. Drawing upon my two decades of experience working with individuals with disabilities, I have concentrated on advocating for inclusive education for individuals with deafblindness over the past five years. This involvement has allowed me to work closely with both congenital and acquired cases of deafblindness, affording me firsthand insight into the barriers they encounter in accessing education.

Through interactions with students with deafblindness, it has become evident that they often grapple with issues such as the lack of assistance during examinations, mistreatment by government officials, and the scarcity of accessible learning materials. Despite my extensive search, academic literature addressing deafblindness and accessibility within the Nepalese context remains elusive. Many students with deafblindness have shared their struggles with obtaining accessible learning resources, navigating examination procedures with the need for assistance writers, and attaining a quality education.

This study seeks to explore the hurdles encountered by students with deafblindness in securing assistance writers for examinations and to shed light on their firsthand experiences during examination participation. Furthermore, it aims to examine current policies regarding the education of students with deafblindness and evaluate their implementation status.

Deafblindness

Deafblindness is a unique disability characterized by the simultaneous loss of both auditory and visual senses. It manifests as a condition where individuals experience disabilities in both hearing and vision concurrently (Joshi, 2023). This combination of sensory impairments is present within the same individual. World Federation of the Deafblindness(WFDB, 2023) defines deafblindness based on the Nordic definition as a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for

each other. In interaction with barriers in the environment, it affects social life, communication, access to information, orientation, and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as interpreter-guides/Deafblind interpreters, among others.

The hearing and vision deficits within the same person create challenges in communication, fulfilling daily life needs, and accessing education. These individuals often struggle during examinations due to the gradual decline in their auditory and visual capabilities. This decline hampers their ability to engage in conversations with others, carry out their daily routines, pursue education, and even independently navigate their surroundings. Thus, they often require assistance from others. Deaf blindness results in a functional limitation in an individual's visual and auditory processing. This leads to difficulties in communication, orientation, mobility, education, health, and overall quality of life. This phenomenon is sometimes referred to as multi-sensory impairment or dual sensory loss (MOWCSC, 2019). Based on the difficulty in auditory and visual capabilities, deafblindness can be classified into four categories.

Complete Deafblindness (Visual and Auditory)
If an individual is unable to hear completely and cannot see fully, they are classified as having complete deafblindness. This condition can be present from birth or can develop later in life (Disability Right Act 2074). Individuals with congenital or acquired complete deafblindness have different communication needs, supportive systems, and means of interaction. They encounter challenges in daily activities such as using toilets, eating, moving from one place to another, and communicating with others.

Blindness and Hard of Hearing
When an individual is unable to see fully but can hear partially, or they can hear with the use of hearing aids or cochlear implants, this condition is known as complete visual impairment and partial hearing (MOWCSC, 2074). Individuals with this type of impairment can develop language skills through speech and can learn Braille. Even though they have visual impairment, they can communicate verbally and express themselves, and with the assistance of others, they can communicate using a louder voice, Braille, and finger spelling.

Deafness and Low Vision
If an individual cannot hear fully and can only see partially or has low vision either with or without using glasses, this condition is referred to as external and limited vision. Individuals with this type of impairment can communicate using sign language and read enlarged text using magnification aids (Disability Right Act 2074). Deafblind individuals in this category can communicate using sign language with those nearby and communicate through sign language, Braille, or large print when they move closer to the individual.

Hard of Hearing and Low Vision
When an individual has partial hearing and limited vision, meaning they can hear with the assistance of hearing aids or cochlear implants and can see to some extent, either with the help of glasses or without, this is known as partial hearing and limited vision. Individuals in this

category can hear to some extent and can also see partially. Their language development is influenced by the assistance of hearing aids and glasses (MOWCSC, 2019). They may not understand spoken words clearly due to unclear sounds, especially in crowded environments, and may need to get closer to listen or read large print using their hands while communicating with individuals. This article introduces a subset of individuals with deafblindness who also belong to the Blindness and Hard of Hearing group. Despite possessing effective communication skills in spoken language, these individuals face limitations in both hearing and seeing due to their combined sensory impairments. Those who experience congenital blindness and acquire hearing impairment encounter even greater communication challenges, which significantly impact their educational pursuits and daily activities. Among individuals who are blind and hard of hearing, there is a greater need for accessibility in the classroom compared to other students (WFDB, 2023).

Methodology

This article presents a phenomenological study that delves into the experiences of three individuals with deafblindness. Given the limited existing literature on this subject, identifying previous research gaps proved challenging. Consequently, the findings of this study are expected to offer fresh insights for scholars, shedding light on the unique experiences of this demographic. The study employed a qualitative research method, facilitating an exploration of the participants' thoughts, feelings, and experiences regarding accessible learning materials in classrooms catering to learners with deafblindness. Through active participation in examinations alongside an assistant writer, the researcher gained firsthand insight into the behaviors exhibited by campus administration.

By adopting a qualitative approach, the researcher was able to document and comprehend the participants' perspectives, opinions, barriers, and struggles encountered within the educational setting, including their methods of participation and exam submission.

A phenomenological design was chosen for its capacity to provide a deeper understanding of lived experiences. The total sample of the study was three participants who are studying in bachelor's degree in education discipline and have total blindness and hard of hearing. They all faced the problem of participating in an exam with the assistant writer and have not access in learning resources in classroom. Purposive sampling was applied in the selection of the participants. Data were acquired through semi-structured interviews with three deafblind students. After getting consent from the participants, audio-visual recordings were recorded. As I previously stated, we ware well familiar, and they all discussed their issues, strengths, and life experiences during the interview.

Thematic analysis was employed to examine the data in alignment with the research objectives. The recorded audio was transcribed into text and subsequently coded. These codes were then grouped into themes as part of the coding strategy. Data tags were utilized, employing phrases and sentences to define and capture the essence of each data point. The information collected during this study was structured into thematic categories. Some of the participants' responses were initially encoded before being organized into overarching topics.

Thematic analysis, as described by (Braun V, 2021), is a method for identifying, analyzing, structuring, characterizing, and reporting the prevalent themes within a dataset. Thematic analysis was chosen due to its suitability for exploring diverse viewpoints among research participants and for highlighting both commonalities and variations in the presented data.

Results

Inclusive education: policy, not practice

Numerous obstacles severely hinder the participation of individuals with deafblindness in various aspects of life, notably education and communication. Education, a foundation of personal development, is constitutionally guaranteed in Nepal (Nepal Law Commition, 2072) and emphasized in international agreements like the Convention on the Rights of Persons with Disabilities (Rutherford, 2023) and the Sustainable Development Goals (Statistics, 2019). Despite legislative efforts to create a barrier-free society in Nepal, effective implementation remains lacking, leaving those with severe disabilities facing significant challenges.

Participants in this study shared distressing experiences related to their education, citing inaccessible classrooms, insufficient Braille materials, and fast-paced teaching that neglects their needs. Requests for accommodations, such as louder speech or slower teaching, often go unmet, with teachers prioritizing non-disabled students. Environmental factors like noise compound these challenges, hindering comprehension and note-taking during classes. A critical issue highlighted by participants is the delayed access to Braille books, particularly in primary education, impeding their learning progress. This deficit persists into higher education, further limiting access to essential course materials and negatively impacting academic achievement.

Of particular concern is the restriction on writing in Braille during exams, forcing participants to rely on assistance writers. This not only adds undue stress but also contravenes their right to an inclusive educational environment. These findings underscore the urgent need for educational institutions and policymakers to address these barriers, ensuring timely access to Braille materials, audio books, and appropriate exam accommodations for individuals with deafblindness.

The assessment procedure is not practical for children with deafblindness

A person who cannot see and has hearing difficulties, such individuals study through Braille textbooks. They can write just like others using computers, not only using slate and stylus. In addition, such individuals can read and write using other digital devices, such as a Braille reader. In Nepal government authorities who makes policies does not aware about the needs of deafblindness to get the education. They don't seem to consider factors like the examination system and the educational materials required.

*The people who decide how to create courses and conduct exams don't seem to know much about us. Why don't they provide suitable learning materials for us? We spend the whole year using Braille to read and write, but when it's time for exams, they don't let us write in Braille. Even government employees or teachers who don't understand Braille script, because of this, we are not allowed to write in Braille. This is frustrating, ... felling angry......... It seems like the education policymakers don't respect us as human beings (*Participant 3*)*

Administrators, educators, and visually impaired students encountered various difficulties within an inclusive classroom. These challenges encompassed ineffective teaching approaches, limited classroom instruction time, a scarcity of educational materials, the absence of specialized educators for visually impaired students, and inadequate infrastructure, particularly in restroom facilities (Zangi & Annie, 2021).

As the exam date approaches, most students become more focused on their studies. However, our experience is different as we need to find an assistant writer. Finding an assistant writer who is in a lower class is quite challenging. Once we find a writer, we need to have them verified by the exam center chief. To facilitate this process, our campus provides us with a recommendation letter, which we must present to the exam center chief. Sometimes, the chief is not available in the office, and we must visit there repeatedly. This creates a lot of trouble for us (Participant 1)**.**
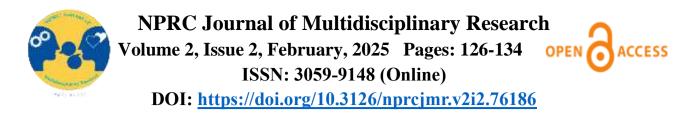
When I was in class eleven, I had prepared all the necessary documents for an assistant writer for my exam and submitted them to the exam center chief. However, at the last minute, the chief canceled my assistant and asked me to find another one, even though my campus had provided me with a recommendation. There were only two days left until the exam, and I couldn't find a new writer in time, resulting in me missing my first exam ((Participant 1)*.*

I requested numerous times to chief to reconsider his decision, but he didn't respond positively. He simply stated, "This is not my problem; it's yours. If you find another writer, you can participate in the exam; otherwise, you can't." Many students face similar problems multiple times (Participant 2)**.**

Assigning an assistant writer during the examination is a discriminatory practice by policymakers towards individuals with deafblindness. This occurs because either the person grading the exam lacks the necessary skills or doesn't understand Braille. Consequently, deafblind students are not permitted to write in Braille, and instead, an assistant writer is required to do the writing.

*Individuals without disabilities who take exams often need to think carefully and reread questions multiple times. However, for deafblind students, the situation is even more challenging as they cannot read the questions independently. They rely on assistants to understand the questions and formulate their answers. Assistant writers should have a lower academic level than the students, and they may struggle with writing long words and technical terminology. Due to differences in writing speed and understanding, students with deafblindness often do not achieve satisfactory results in exams (*Participant 3*).*

Discussions about inclusive education began in Nepal almost a decade ago. However, the understanding of inclusiveness or creating a disability-friendly environment still lags. Policy makers often believe that simply building ramps in schools or offices is enough to achieve inclusiveness or disability friendly. Even in educational institutions and among teachers specializing in inclusive education, there is limited awareness about deafblindness. Many have never even heard of the term 'deafblind,' and they lack knowledge about the challenges and

barriers faced by deafblind students. Additionally, some teachers may not even know which types of students are in their classrooms. Their teaching strategies are primarily focused on nondisabled students.

When deafblind students request certain accommodations, such as having the teacher stand nearby, speak loudly, or speak at a slower pace, their requests are often denied. This is because teachers feel pressured to complete the curriculum within a specific timeframe, regardless of whether deafblind students can keep up with the pace or not. These statements are based on the participants' opinions expressed during the interviews, reflecting their deeply felt concerns.

> *We live in the digital age, and I can operate a computer if screen reader software is installed. If the exam proctor doesn't know Braille, they should provide us with computers for the exam. In all the exam centers, there were computers available. However, we are restricted from using computers, even though computer use is a part of inclusivity. In Nepal, inclusive education is like HATTI KO DEKHAUNE DANT. On paper, everything looks great in the policies, but in practice, it's the opposite. In all of Nepal, there is no inclusive setting to be found in schools* (Participant 2)**.**

Education Regulation 2059, Section 47 mentions that children with disabilities have the right to participate in exams using whichever language or script they prefer. The regulation also provides the exam center chief the authority to grant additional time to students with disabilities who face difficulties or take longer to complete their exams.
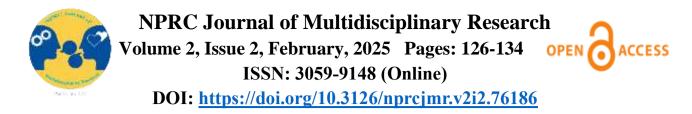
> *I had requested the exam center chief multiple times to grant me additional time, but they denied my requests and told me to write as much as I could within the given time. Nowadays, I no longer make such requests. Due to time constraints, I couldn't answer all the questions in the exam, even though I knew the answers. If I were given additional time or permission to write on a computer or in braille, I believe I could answer more questions and take pride in my active participation in the exam* (Participant 1).

Discussion

Drawing from both my prior experience in the field of deafblindness and insights shared by participants, it's evident that students facing deafblindness confront myriad challenges within their educational journey. These hurdles range from inadequate classroom resources to encountering unwelcoming attitudes from educators, along with grappling with examination systems that fail to accommodate their unique needs (Zangi & Annie, 2021).

While Nepal has ratified various international agreements and instituted national policies aimed at enhancing disability rights and education, such as the Convention on the Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs), alongside domestic frameworks like the National Education Policy of 2076, Education Regulation of 2059, and the School Education Sector Plan (SESP) of 2078, significant barriers persist hindering students with deafblindness from accessing quality education.

One such obstacle is the absence of provision for an assistant writer during exams, imposing a considerable financial burden on students with blindness who must cover expenses

related to travel and daily service fees. Securing a suitable writer further compounds the challenge, often necessitating approval from the exam center and grappling with language barriers, where a writer proficient in English script may struggle with transcribing responses in Nepali script, leading to incomplete answers and compromised performance. Dependence on assistant writers for equitable examination experiences is paramount for students with deafblindness, yet instances of errors such as erroneous attendance markings due to writers' lack of commitment have been reported, resulting in failed exam outcomes. Addressing these issues is pivotal in ensuring equitable educational opportunities for students with deafblindness.

When examining the concept of inclusive education, it becomes apparent that while policies promoting inclusivity exist, their implementation in educational institutions remains deficient. Many lack inclusive learning materials, accessible infrastructure, and appropriate pedagogical approaches due to a lack of commitment from policymakers and implementing authorities. This disconnect underscores the need for a paradigm shift and a deeper understanding of disabilities at all levels of the education system. Policies must be translated into actionable strategies, with educational institutions equipped with necessary resources and training to foster a truly inclusive educational environment, accommodating all students regardless of their abilities or disabilities.

Conclusion

The realization of inclusive education, as outlined in policy, remains a formidable challenge within educational institutions. The absence of inclusive resources, accessible infrastructure, and appropriate instructional approaches poses significant barriers to the practical implementation of these policies. A fundamental issue lies in the limited understanding of disabilities, such as deafblindness, among policymakers and implementers. Often, inclusive education is viewed as a peripheral concern rather than an integral part of their responsibilities, further complicating the implementation process. To truly actualize inclusive education, a paradigm shift is imperative. Policymakers and educators must recognize that it transcends mere policy rhetoric, constituting a fundamental moral and legal obligation. Collaborative efforts are needed to translate policies into actionable strategies, accompanied by the provision of requisite resources and training. Through this concerted approach, we can cultivate a genuinely inclusive educational milieu wherein every student, irrespective of their abilities or disabilities, can flourish. Such a transformation is pivotal in bridging the chasm between policy aspirations and practical realities, ensuring that inclusive education becomes a tangible reality for all.

Furthermore, it's imperative for the government to explore alternative examination systems for children with deafblindness, rather than relying solely on assistant writers. The dependence on such writers not only contravenes human rights and constitutional principles but also perpetuates inequitable educational practices. Despite being a minority, children with deafblindness are entitled to the same educational rights and accommodations as their peers, underscoring the urgent need for systemic reform in examination procedures.

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