

Unveiling the Overlooked: A Comprehensive Review of Deafblindness in India

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ABSTRACT

Deafblindness, characterized by dual sensory impairment in both hearing and vision, presents significant challenges to affected individuals and is considered a highly vulnerable condition. This study focuses on the status of Deafblindness, particularly in India, where it has only recently been recognized as a distinct disability under the RPWD Act, 2016. However, there remains a scarcity of research and development efforts in this field. Multiple studies indicate the presence of mental health issues like depression and perceived lack of social support among individuals with Deafblindness. In India, deafblind individuals face discrimination and limited access to essential resources and services. The study emphasizes the need for rehabilitation in various areas, including communication, mobility, information access, and psychological adaptation. Protactile communication has emerged as a promising approach, but there is a lack of training modules and research in India. There are significant inventions globally, including some in India, designed to enhance mobility and learning for deafblind individuals. However, these products suffer from a lack of promotion and information dissemination. Additionally, challenges persist in providing adequate counseling due to existing communication barriers. The study highlights critical areas that require attention to better rehabilitate deafblind individuals and create a more inclusive world for them in the future.

Keywords: Deafblindness, Disability, Protactile, Rehabilitation

INTRODUCTION

Disability refers to a state in which an individual experiences challenges in performing specific activities due to impairments in their body or mind. It also involves difficulties in engaging with the surrounding world, leading to limitations in participation (Centers for Disease Control and Prevention, 2019). The World Health Organization explains that disability encompasses three dimensions for a comprehensive understanding. These dimensions include physical impairments in specific body structures or parts, restrictions in carrying out activities, and limitations in participation.

Having a disability related to a single sensory impairment can significantly affect an individual's life. However, the challenges become even more profound when someone experiences sensory deficits in multiple areas. Deafblindness is an example of a dual sensory impairment that involves different levels of hearing loss and limited vision. The impact of Deafblindness goes beyond a simple combination of the effects of the two disabilities; it is significantly multiplied (Shetye, 2019). A child with Deafblindness faces considerable difficulties in processing both visual and auditory information, which adversely affects their communication, learning, mobility, socialization, and daily living skills (Jaiswal et al., 2019). As a result, not only do their overall functioning and activities become compromised, but their ability to actively participate in society is also significantly limited. Deafblindness is a lifelong condition, and the severity can vary along a

spectrum based on the extent of visual and auditory impairments.

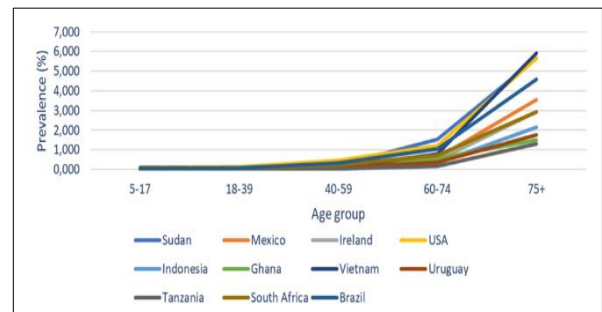


Figure 1: Late-onset Deafblindness is more prevalent across countries

Source: World Federation of the Deafblind Report (2018)

Deafblindness can be congenital as well as acquired and the latter is the most prevalent one among the two (Minhas *et al.*, 2022). Down syndrome, hydrocephaly, congenital rubella syndrome, and microcephaly are common causes of congenital deafblindness while later acquired Deafblindness to postnatal meningitis, usher syndrome, asphyxia, and head injury (Sundqvist *et al.*, 2022). Deafblindness is also classified as prelingual (usually congenital or acquired during infancy before language development) and post-lingual (acquired during childhood or adolescence after language development) and this has significant implications on the later communication training processes. We usually learn things through our eyes and ears and express them through our speech. People without visual and auditory functioning are disabled in terms of learning and

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acquiring information about the world and eventually, do not learn ways to express their needs. Deafblindness is not just a state of dual sensory impairment but is a lot beyond that.

Status of Deafblindness in India

Despite the existence of Deafblindness in India since the early 1800s, there is a significant dearth of research in this field. Imchen (2022) reports that an estimated 500,000 individuals in India have Deafblindness, and currently, Sense International India is the only organization providing national-level education and rehabilitation services for the deafblind community for the past 26 years. The prevalence of congenital Deafblindness is high in India due to a considerable number of diagnosed cases of congenital rubella syndrome each year. However, there is a notable scarcity of published research and established rehabilitation programs focused on Deafblindness in the country, resulting in persistent life dissatisfaction and marginalization (Jaiswal et al., 2019). Paul et al. (2020) further state that although Deafblindness is not a rare condition in India, a majority of children and adults with Deafblindness receive late diagnoses and lack access to necessary services. Additionally, there is a lack of assessment tools and educational frameworks tailored for the deafblind population. Until 2016, Deafblindness was not officially recognized as a distinct disability at the national level, leading to limited accessibility to social welfare services. However, through the advocacy efforts of Sense International India, Deafblindness has now been recognized as a separate disability under the Rehabilitation of Persons with Disabilities Act of 2016 (Imchen, 2022).

Currently, Sense International India is actively engaged in enhancing research, interventions, and policies concerning individuals with deafblindness and their families. They operate three national networks, namely UDAAN, PRAYAS, and ABHI-PRERNA, with a focus on increasing and improving support for the deafblind community. Specialized communication methods and therapies are being utilized for education and rehabilitation purposes. However, there remains a pressing requirement for extensive research and development efforts in this field.

Psychosocial Issues in Deafblindness

“Blindness separates us from things but deafness separates us from people” - Helen Keller

When an individual experience a single sensory impairment, the remaining senses often compensate to some extent, helping them cope with the situation. However, in the case of Deafblindness, where both major senses involved in perceiving the world are impaired, the challenges can lead to unimaginable distress.

Unfortunately, there is a shortage of competent researchers in this field, resulting in a lack of psychological studies on Deafblindness. Nevertheless, the existing research indicates that individuals with Deafblindness often report feeling socially isolated and lonely. Despite their strong desire to contribute to society, they often feel insignificant due to communication barriers (Hersh, 2013). Some studies have highlighted that Deafblindness is one of the most vulnerable conditions, associated with significant levels of depression, perceived stigma, and a lack of social support among those affected (Bodsworth et al., 2011; Simcock, 2016).

Khil et al. (2015) discovered that in individuals with Deafblindness, there is a significant correlation between depression and various factors, such as limited mobility, difficulties in social interactions, and restrictions in participation, all of which ultimately contribute to a lower quality of life. Deafness itself plays a significant role in their feelings of isolation, as it prevents them from connecting with others, leading to increased loneliness (Hersh, 2013). Additionally, the perception of social support plays a crucial role in the psychological well-being of distressed individuals with Deafblindness. Research has shown that those who lack social support are more prone to experiencing clinical depression and having an overall poorer quality of life (Santini et al., 2016).

Deafblindness does not just impact the individual but also extends to their family members. The person's dependence on family members is often high due to the challenges in acquiring knowledge and daily living skills (Dean et al., 2017). Unfortunately, the lack of caregiver training in handling Deafblindness leads to communication difficulties and frustration on both sides. Sometimes, caregivers become overwhelmed with their responsibilities and identify solely with the caregiver role, which can strain their relationship with the deafblind person. This frustration might also get displaced onto the deafblind individual, leading to unwarranted blame and abuse for their disability, for which they bear no responsibility.

Society significantly impacts the quality of life of individuals with Deafblindness. According to Raghavan (2021), deafblind persons in India face daily challenges of discrimination and lack of access to essential services and aids. Eminent deafblind individuals have reported that on social media, many people doubt the credibility of successful deafblind individuals, as they find it hard to believe that someone with dual sensory impairment can work on par with someone without disabilities. These stereotypes and lack of awareness hinder the development of crucial tools like alternative communication devices and mobility aids, pushing

deafblind individuals further into distress, hopelessness, depression, and poverty.

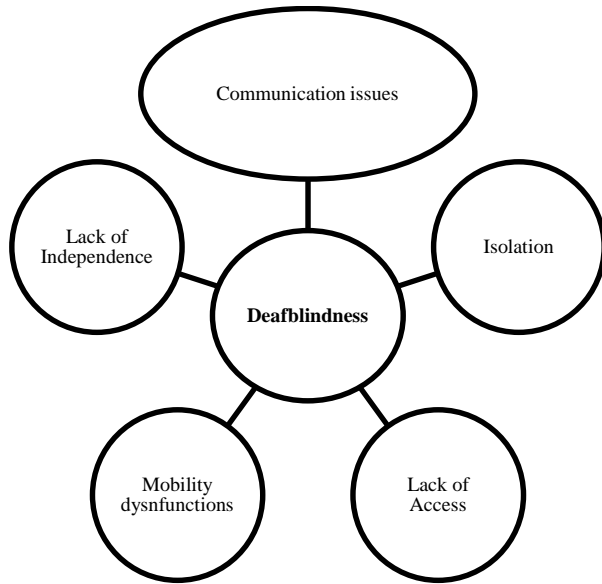


Figure 2: Psychosocial issues in Deafblindness
Source: Hersh (2013)

While Deafblindness is more commonly associated with old age, its impact on children with early onset or congenital Deafblindness is particularly severe. This condition hinders their education, learning of daily living skills, language development, communication, and cognitive growth, making it challenging for them to learn sign languages, which could aid in their intervention later. Clinical studies have shown that mild cases of Deafblindness in children are often misdiagnosed as autism spectrum disorder due to similarities in communication abnormalities and sensory processing challenges (deVann et al., 2019). These misdiagnoses also highlight the importance of raising awareness and conducting further research on Deafblindness to facilitate early identification and intervention. Recognizing and addressing Deafblindness promptly becomes crucial to providing the necessary support and care for affected individuals (Moroeet al., 2022).

Psychosocial Rehabilitation

An effective rehabilitation program plays a crucial role in addressing the disparity between an individual's capabilities and societal expectations. For individuals with Deafblindness, a specialized psychosocial rehabilitation program is of utmost importance. Despite gradual progress in research and development, several rehabilitation techniques and intervention programs have emerged to cater to the unique needs of deafblind individuals. Extensive literature reviews indicate that these rehabilitation efforts are designed to focus on specific areas of functioning, aiming to optimize the

person's abilities and enable them to lead a fulfilling life in the broader community (Warnicke et al., 2022).

In the initial stages of deafblind rehabilitation, Nelipovich & Naegele (1985) introduced a rehabilitation model in their research. They suggested that due to the limited understanding of the condition and the available support services, the rehabilitation process should commence with establishing strong relationships and connections with various institutions like schools, hospitals, etc. This would help identify individuals in need and facilitate their referral for psychosocial rehabilitation. Subsequently, a thorough intake process, diagnosis, evaluation, and comprehensive adjustment training would be implemented. The adjustment training services provided in deafblind rehabilitation focus on enhancing the individual's personal and interpersonal functionality while also aiming to improve their employability through pre-vocational and vocational training. Rehabilitation counseling played a significant role during this period, with counselors assisting individuals with Deafblindness in effectively utilizing their personal and environmental resources (Hammer & Edwin, 1974). It was widely recognized at that time that learning effective communication methods with deafblind individuals was an essential initial step in the rehabilitation process, regardless of having good intentions and a well-structured model. Although communication methods such as "Braille hand speech," "Talking disc," and "Tell a touch machine" showed success with some individuals who had mild deafness or blindness, they often struggled to maintain a consistent flow of communication in many cases (Nelipovich & Naegele, 1985).

In the current scenario, psychosocial rehabilitation programs usually focus on improving functioning in the areas of communication, learning information, mobility and psychologically adapting to the condition of Deafblindness. Certain developments in these areas have been mentioned below:

- **Communication:** Recent research has highlighted tactile communication as the most effective modality for deafblind individuals. Advancements in technology have led to the development of innovative products, such as Vibrotactile gloves, designed to convert messages from smartphones and computers into vibrations felt on the fingers. These vibrations, varying in frequencies, require decoding for understanding the information (Shivakumar & Rajasenathipathi, 2014). Studies indicate that with sufficient practice, approximately 97% of deafblind individuals accurately decoded these messages (Carrera et al., 2017). Additionally, Hussain et al. (2019) designed a mobile app called Smart Prayer Aid, which converts spoken prayers into vibrations

and delivers them through a smartphone or smartwatch via voice recognition. Participants placed the smartphone in their front pocket or wore the smartwatch on their right wrist. This technology not only facilitated easier concentration on religious spirituality but also allowed participants to synchronize their movements with the Imam without external assistance.

Some other studies were also conducted on the effectiveness of aromatherapy and therapeutic massage on self-confidence, communication, and well-being of deafblind persons. It was found that post intervention the participants seemed more sociable, outgoing, and more comfortable with tactile contact, and their communication skills and confidence also increased. One of the most current techniques being used for Deafblindness is Protactile language which is based on the recognition that Deafblind individuals possess more pronounced intuitions regarding tactile communication compared to the intuitions of sighted people (Granda & Nuccio, 2018). Protactile communication utilizes the sense of touch (haptic system) to convey and receive visual, environmental, and social information through tactile signals on the body. Wing (2022) emphasized that many deafblind individuals attempted to use variations of sign languages for communication, but these languages were designed primarily for a single sensory impairment, resulting in them only understanding half of the world. Even iconic figures like Helen Keller utilized finger spelling, a modification of American Sign Language and Braille, which still had significant limitations.

In response to this challenge, Fidrocki (2018) noted that the deafblind community came together and initiated a language revolution, led by Lard and Dwyer, two deafblind individuals. They created a new language that broke away from the traditional concept of language expressed through sounds and sight, focusing instead on the linguistic qualities of touch. This innovative approach, known as protactile, involves people holding each other's hands to interpret learned American signs through touch, utilizing tapping for backchanneling and responding with signing.

Nuccio (2018) highlighted that this protactile communication, also referred to as Protactile American Sign Language or Protactile ASL, is gradually gaining traction among deafblind communities, and in India, the efforts of organizations like Sense International India are also making deafblind people learn the same.¹¹ Additionally, an app called Good Vibes has been introduced in India, combining Morse code and smartphone vibrations to assist deafblind individuals in communicating through protactile means (Mitter, 2019). While the app may still have some imperfections, such

innovative endeavours offer hope for making communication slightly easier for the deafblind community.

Mobility: The impairment in sight and hearing also limits the ability to move around freely, especially outside the house. Bourquin and Moon (2008) conducted research on deafblind individuals and discovered that using a large card with text and illustrations of a person assisting another to cross the road is an effective way to seek social assistance for them. To aid with directions both inside and outside their homes, Lancioni et al. (2010) found that the use of vibrotactile boxes and eyeglasses equipped with vibrators can help deafblind individuals understand the correct directions by signaling through vibrations.

In another study by Vincent et al. (2013), a new device called Miniguide was identified as beneficial for deafblindness. This device utilizes an Eco localization system to detect obstacles and communicates through vibrations to alert the individual. Furthermore, Nadal and Iglesias (2018) conducted research on rehabilitation programs for deafblind individuals and found that comprehensive programs including support groups, vocational training, assistive technologies, and mobility & orientation training significantly contribute to improving the well-being, independence, and adaptiveness of deafblind persons.

Accessibility to information: The dual sensory impairment in deafblindness makes information comprehension and access challenging. Not only it affects their knowledge acquisition and vocational skills but also affects their quality of daily activities. Rehabilitation in this regard must focus on planning educational models that can bridge the sound-sight barrier and make information accessible for deafblind persons. Batanero et al. (2019) documented a successful case of an inclusive educational platform called Moodle. This platform provided detailed image descriptions, audio support, screen readers, and device integration to translate text into Braille, thereby enhancing accessibility for deafblind individuals.

Another device named GoAll is also being used frequently globally and through this device, the texts and captions from Television or mobile can be read through a braille device (García-Crespo *et al.*, 2020). It has been reported that these devices mainly aid persons with acquired Deafblindness as a basic knowledge of braille is necessary to decode the converted information. After understanding the information through braille, these people can respond through protactile signing.

Psychological adaptation to the condition: It is tough to accept and adapt to such a disabling condition as Deafblindness. Various research shows the presence of

psychiatric morbidity in deafblind individuals despite a lack of proper assessment due to a lack of trained clinicians. The role of a Clinical Psychologist is high in this area due to its sensitivity and the necessity of a specialized mental health professional. Cote *et al.* (2013) reported that specialized psychological group intervention focusing on personal goal fulfillment has been found to be effective in increasing well-being, resilience, self-determination, and ability to plan & pursue a goal.

However, providing psychological intervention in Deafblindness faces significant obstacles, primarily due to the language barrier and a lack of training in protactile communication. Molander *et al.* (2017) noted that while internet-based Acceptance and Commitment therapy has shown effectiveness in increasing acceptance and well-being for those with hearing impairment, the lack of knowledge in tactile communication hinders similar intervention-based research for deafblind individuals.

Despite various rehabilitation programs and innovations being developed in different countries, India still faces a significant shortage of research and interventions for deafblindness. Currently, Sense International India is the sole organization officially conducting diverse rehabilitation programs that focus on communication, vocational skills, social support, awareness enhancement, and education. However, a major challenge in India is the lack of research and awareness concerning this disability. Consequently, a large portion of the population remains unaware of its existence, let alone the available rehabilitation measures (Senseintindia, 2023).

CONCLUSION

Deafblindness refers to the condition where individuals experience a combination of hearing and vision loss, posing considerable difficulties for those affected. Communication, learning, mobility, and psychological adaptation are severely impacted, leading to social isolation and marginalization. Despite some developments in rehabilitation programs and interventions globally, India faces a significant scarcity of research and awareness on deafblindness. Sense International India is the only organization in the country officially conducting rehabilitation programs, but the lack of resources hinders widespread support. The psychosocial issues related to deafblindness are profound, with individuals experiencing depression, loneliness, and a lack of social support. Caregivers also face challenges in understanding and supporting the deafblind person. However, some advancements have been made in communication techniques, mobility aids, and psychosocial interventions, providing hope for improved rehabilitation. Nevertheless, there is an urgent need for extensive research and development efforts to

enhance the quality of life and well-being of individuals with deafblindness in India.

The current study highlights several crucial issues that demand attention. Firstly, there is a need for extensive state and national campaigns and awareness programs to educate people about deafblindness and the specific challenges faced by individuals with this condition. These initiatives should emphasize the collective responsibility of all Indians in providing support and aim to eliminate the existing stigma associated with Deafblindness.

Secondly, it is essential to encourage medical and mental health professionals to learn protactile sign language. By doing so, they can conduct more effective research and offer appropriate interventions for deafblind individuals without being hindered by communication barriers. Establishing additional organizations similar to Sense International India would further contribute to the advancement of Deafblindness-related initiatives. These organizations should also provide courses to train people in protactile sign language, enabling deafblind individuals to communicate beyond their immediate community.

Furthermore, the present research has predominantly focused on individuals with acquired deafblindness, who had the opportunity to gradually adapt to their condition and learn various communication techniques over time. However, there is a lack of information concerning how individuals with congenital deafblindness acquire tactile-based language skills since they may not have the same opportunity to learn sign language. Therefore, further research is imperative to encompass the entire spectrum of both congenital and acquired deafblindness.

Moreover, it is worth noting that India has seen some innovations, like Good Vibes, aiming to assist deafblind individuals in their rehabilitation process. However, the lack of sufficient media exposure for such inventions results in a lack of awareness among the general public. To address this, it is essential for prominent media outlets to take the initiative in promoting these inventions and developments, ensuring that deafblind individuals and their caregivers can access the available support.

Lastly, the rehabilitation of a deafblind person requires a multidisciplinary approach with involvement from various stakeholders. This includes social workers, entrepreneurs, medical and mental health professionals, media representatives, and government officials. Each of these parties has a significant role to play in creating an inclusive and harmonious world for individuals with deafblindness, taking on their respective responsibilities to facilitate a better quality of life for them.

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