



CREATING AN ACCESSIBLE ENVIRONMENT FOR PERSONS WITH DEAF-BLINDNESS: THE INTEGRAL ROLES OF PROFESSIONALS AND CAREGIVERS

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Abstract

Persons with deaf-blindness, a heterogeneous group with varying degrees of combined vision and hearing loss, face profound challenges in accessing information, communication, and navigating physical and social environments. Creating a truly accessible environment for this population requires a multifaceted, person-centered approach that extends beyond physical modifications to encompass communication, social interaction, and psychological well-being. This paper explores the concept of accessibility through the lens of deaf-blindness, arguing that it is a dynamic process co-constructed by a collaborative network of professionals and caregivers. It delineates the specific, yet interconnected, roles of key professionals including intervenors, teachers of the deaf-blind, orientation and mobility (O&M) specialists, speech-language pathologists, and occupational therapists in assessing needs, building skills, and facilitating access. Simultaneously, it highlights the indispensable role of caregivers (both familial and paid) as constant facilitators, communicators, and advocates who translate professional strategies into daily life. The paper concludes that sustainable accessibility is only achievable through a synergistic partnership where professionals equip and empower caregivers, and caregivers provide the continuous implementation and feedback necessary for genuine inclusion. Recommendations for interdisciplinary training and systemic support are provided.

Keywords: Deaf-blindness, Accessibility, Intervenor, Tactile communication, Orientation and Mobility.

Introduction

National Center on Deaf-Blindness (2018) defines Deaf-blindness as a unique disability, constituting not merely the sum of vision and hearing loss, but a distinct condition that creates significant challenges in accessing information, communicating, and interacting with the world. The term encompasses a vast spectrum, from individuals with mild hearing and vision loss to those with profound losses in both senses. This heterogeneity necessitates a highly individualized approach for support and accessibility. Center for Parent Information and Resources (2020) defines deaf-blindness as a distinct disability defined by a combination of vision and hearing impairments that severely limits access to auditory and visual information, creating unique challenges for communication, mobility, and learning. It is not a monolithic condition but a spectrum affecting an estimated 30 million individuals globally, with prevalence expected to rise due to age-related causes. The heterogeneity of this population encompassing varying degrees of sensory loss, congenital (present at birth) and acquired (occurring later in life) conditions demands a rejection of one-size-fits-all solutions (Jarry, 2024).

The concept of an "accessible environment" for a person with deaf-blindness transcends the conventional understanding of ramps and Braille signs. It is a holistic construct involving the systematic

removal of barriers across multiple domains: the physical environment (navigating spaces safely), the communicative environment (exchanging information effectively), and the social environment (fostering relationships and participation) (Dalby et al., 2009). Without intentional design and support across these domains, individuals with deaf-blindness risk extreme isolation, learned helplessness, and a diminished quality of life.

This paper posits that the creation of such an accessible environment is not the sole responsibility of any single entity. Rather, it is a dynamic, co-created process reliant on a robust partnership between a diverse team of professionals and the dedicated caregivers who support the individual daily. Moller & Danermark (2007) observes that while professionals bring specialized knowledge and assessment skills, caregivers provide the consistency, context, and deep personal knowledge that make accessibility strategies functional and sustainable.

Understanding Deaf-Blindness and Its Implications

Deaf-blindness is defined by the Individuals with Disabilities Education Act (IDEA) 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" (IDEA, 2004). Common

etiologies include congenital conditions like Usher Syndrome (leading to deafness and progressive vision loss from Retinitis Pigmentosa), CHARGE syndrome, and prenatal infections such as Congenital Rubella, as well as acquired causes like aging, illness, or trauma (Dammeyer, 2014).

The Impact of Deaf-blindness on Learning and Interaction

The combined sensory loss creates a "barrier to the world" that fundamentally alters development and learning. Vision and hearing are the primary "distance senses" that provide incidental learning—the constant, unconscious absorption of information from one's surroundings (Miles, 2003). A child who is deaf-blind does not overhear conversations that build language, see a smile of approval from across the room, or observe how others navigate a doorway. This results in a need for systematic, intentional teaching of concepts that sighted-hearing children learn naturally.

The Need for a Co-Created Environment

The environment in which persons with Deaf-blindness lives does not become accessible on its own; it must be made accessible through deliberate acts. This involves:-

- **Providing Information:** Converting auditory and visual information into a format the individual can perceive, typically through touch (tactile signing, objects of reference) or residual senses.
- **Ensuring Predictability:** Establishing routines and cues to help the individual

understand what is happening and what will happen next, reducing anxiety and promoting agency.

- **Facilitating Communication:** Creating a "communication-rich environment" where the individual's expressive attempts, however subtle, are recognized, honored, and responded to (Nafstad & Rødbroe, 2015).

The Professional Network: A Multidisciplinary Framework

No single professional holds all the answers for supporting a person with deaf-blindness. A team approach is essential, with each member contributing a unique piece to the accessibility puzzle. Core members of this professional network typically include:

Educators and Rehabilitation Specialists

Teachers of the Deaf-Blind: They design and implement individualized educational plans, focusing on alternative communication systems, concept development, and curriculum adaptation. Resources like the National Center on Deaf-Blindness and state deaf-blind projects offer essential guidance for educators (Center for Parent Information and Resources, 2020).

Orientation & Mobility (O&M) Specialists: They teach safe travel techniques adapted for dual sensory loss, which may include human guide, cane use, and mental mapping with tactile cues. (Högner, 2022).

Speech-Language Pathologists & Technology Specialists: They assess and develop individualized communication systems, which may include formal training in Protactile language (a communication method based on touch and movement developed by the deaf-blind community), braille, or the use of augmentative and alternative communication (AAC) devices (Vanderbilt University, 2020). They also guide the use of assistive technologies like screen readers, magnification software, and alerting systems.

The Critical Roles of Specialized Training

The effectiveness of professionals working with individuals with deaf-blindness hinges on specialized, ongoing training. Organizations like the Helen Keller National Center (HKNC) offer critical resources, such as free online courses for professionals and caregivers on communication strategies and technology solutions. Similarly, initiatives like Colorado's project for children with combined vision and hearing loss emphasize training professional interveners to achieve national certification, thereby elevating service quality (Center for Parent Information and Resources, 2020).

Primary Communicator and Environmental Engineer

Caregivers are the most constant communication partners. They become proficient in the individual's unique communication methods, interpreting subtle cues and providing a continuous

flow of accessible information. They also engineer the home environment for safety and independence by ensuring clear pathways, consistent placement of items, good contrast lighting, and installing adapted safety equipment like vibration-alert smoke detectors (Carers First. n.d.)

Coordinator, Advocate, and Emotional Anchor

Caregivers act as the central coordinators of the support team, implementing recommendations from O&M specialists, therapists, and educators. They are fierce advocates within educational, healthcare, and social service systems. Perhaps most critically, they provide emotional security and work to combat the profound isolation associated with deaf-blindness, nurturing self-esteem and psychological resilience.

Policy, Advocacy, and Community

Legislative Advocacy: Laws like the Americans with Disabilities Act (ADA) mandate effective communication and accessibility-1. Current advocacy focuses on data-driven policy, such as the proposed Deaf Blind DATA Act in the U.S., which aims to ensure accurate census data on deaf-blind individuals to inform resource allocation (Center for People with Disabilities, 2024)

Community & Culture: Recognizing and respecting Deaf-Blind culture is integral. Celebrating events like Deaf-Blind Awareness Week (the last week of June) and following the leadership of deaf-blind individuals themselves are fundamental to moving

beyond a charity model to a rights-based model of inclusion. (Center for People with Disabilities, 2024)

Policy & Community: ADA/Disability Rights, Advocacy (e.g., DATA Act), Deaf-Blind Culture, Training Resources (e.g., HKNC). Center for People with Disabilities (2024) and Helen Keller National Center (2025), observed that the most effective outcomes arise from a collaborative partnership where professionals and caregivers engage in a continuous exchange. Professionals provide evidence-based strategies and technical training, while caregivers offer crucial contextual knowledge about what works in the individual's daily life. This partnership must be supported by systemic investment in training programs, stable funding for SSP services (addressing critical shortages as seen in states like Colorado), and policy frameworks that recognize the unique nature of deaf-blindness.

Ultimately, an accessible environment is one where the person with deaf-blindness can exercise autonomy, build social connections, and participate fully in society. It is an environment built not just on ramps and braille labels, but on human connections, respect, and the shared commitment to translating the world into a format that is perceivable, understandable, and navigable on one's own terms.

- **The Intervenor:** A role particularly prominent in Canada and increasingly recognized worldwide. The intervenor

acts as a "bridge" to the world, providing access to information and facilitating communication and interaction under the guidance of the individual (Intervenor Services Network, 2020). They are trained in tactile signing, co-active movement, and building trust.

- **The Orientation and Mobility (O&M) Specialist:** This professional teaches skills for safe and independent travel. For a person with deaf-blindness, this may involve human guide techniques, the use of a long white cane with adaptations, tactile maps, and trailing techniques (Pogrud et al., 2012).
- **The Speech-Language Pathologist (SLP):** The SLP assesses communication abilities and needs, working to develop functional communication systems. This can range from developing oral language using residual hearing to implementing complex Augmentative and Alternative Communication (AAC) devices with tactile interfaces (Bruce et al., 2016).

The Occupational Therapist (OT): The OT focuses on enabling participation in daily activities (occupations). They assess sensory processing, recommend environmental adaptations, and teach skills for self-care, thereby promoting autonomy and reducing dependence (Chapparo & Hooper, 2005).

The Indispensable Role of Caregivers

Caregiver whether family members or paid support workers provide the consistent, contextual, and emotional foundation upon which professional

strategies are built and sustained in daily life.

The Roles of the Intervenor and Teacher of the Deaf-Blind

The intervenor is paramount in making the environment dynamically accessible. The intervenor's work is relational and situational. Key functions include:

- **Providing Sensory Information:** Verbally describing or signing into the hand what is happening, who is present, and what environmental sounds mean
- **Facilitating Communication:** The intervenor acts as a communication partner and, when needed, he is relied on for conversations with others, ensuring the individual with deaf-blindness can both express themselves and receive messages from others (Intervenor Services Network, 2020).
- **Supporting Social Interaction:** Guiding the individual in initiating and maintaining social contact, interpreting social cues, and facilitating shared activities.
- **Promoting Concept Development:** Systematically introducing new concepts through real-life experiences, using objects, tactile models, and co-active participation.

The Teacher of the Deaf-Blind: The Architect of Learning

While the intervenor focuses on immediate access, the teacher designs the long-term educational plan. Their role involves:

- **Comprehensive Assessment:** The teacher conducts learning media assessments to determine the best sensory channels for learning (visual, auditory, tactile).
- **Individualized Education Program (IEP) Development:** Creating goals and objectives that target expanded core curricula, including communication, socialization, self-determination, and use of assistive technology (Parker, 2009).
- **Collaborative Consultation:** Training and coaching other team members, including other teachers, paraprofessionals, and caregivers, on effective strategies for interacting with and teaching the student.

The Role of Orientation and Mobility (O&M) Specialists and Sign Language Pathologists (SLPs)

For a person with deaf-blindness, the physical environment can be disorienting and hazardous. The O&M specialist's role is to build confidence and competence in movement. It is the responsibility of this specialist to teach:-

- **Adapted Techniques:** Teaching human guide techniques where the individual holds the guide's arm just above the elbow, receiving information about turns, stairs, and obstacles through the guide's movement (Pogrud et al., 2012).
- **Environmental Familiarization:** Systematically introducing new environments using tactile maps and repeated, structured exploration to build mental schemas of spaces.

- **Assistive Technology for Mobility:** Introducing and training on the use of canes, GPS devices adapted for tactile feed-back or other electronic travel aids.

The Speech-Language Pathologist: The Communication Engineer

The SLP works to build a robust, functional communication system tailored to the individual's sensory abilities and motor skills.

- **System Selection and Implementation:** This can include formal systems like tactile American Sign Language (ASL), Pro-Tactile ASL, fingerspelling into the palm, or Tadoma (tactile lip-reading). It also includes informal systems like gestures, objects of reference, and picture symbols (Bruce et al., 2016).
- **Assistive Communication Technology Implementation:** For some individuals, high-tech ACT devices with dynamic touch screens or switches can be life-changing. The SLP assesses, prescribes, and trains the individual and their team on using these technologies.
- **Pragmatic Skills:** Teaching the social use of communication, such as how to initiate, maintain, and terminate an interaction, even through tactile means.

The Role of Occupational Therapists and Other Professionals

The Occupational Therapists focus on "occupation" the meaningful activities of daily life are crucial for holistic accessibility. It is the responsibility of these individuals to:-

- **Enable Sensory Integration:** Many individuals with deaf-blindness have atypical sensory processing. The OT can develop strategies to help regulate arousal levels, manage sensory overload, or provide needed sensory input (Chapparo & Hooper, 2005).
- **Make Environmental Modification:** Recommending specific adaptations to the home, school, or workplace to increase independence. This could include improved lighting for those with residual vision, tactile markers on appliances, or reorganizing spaces to reduce clutter and simplify navigation.
- **Design Self-Care Skill Development:** Breaking down tasks like dressing, eating, and personal hygiene into teachable steps, using backward chaining and other techniques to foster autonomy.

Other Key Professionals:

- **Audiologists and Ophthalmologists:** Provide critical medical and functional assessments of hearing and vision, and manage interventions like hearing aids, cochlear implants, or optical devices.
- **Rehabilitation Counselors:** Assist with vocational training, job placement, and independent living skills for adults.
- **Social Workers and Psychologists:** Provide emotional support, counseling, and facilitate connections to community resources and support groups for both the individual and their family.

The Indispensable Role of Caregivers

The demands on caregivers are significant, necessitating their own support network. Accessing a Social Care Needs Assessment, connecting with condition-specific organizations (e.g., Sense, Deaf-Blind UK), and joining peer support groups are vital steps to prevent burnout and sustain effective care.

Caregiver whether family members or paid support workers provide the consistent, contextual, and emotional foundation upon which professional strategies are built and sustained in daily life.

While professionals provide episodic expertise, caregivers whether parents, family members, or paid support staff are the constants. They are the primary agents in implementing accessibility strategies 24/7. Their role is multifaceted and profound.

Primary Communicator and Interpreter of the World

Caregivers are the most frequent and trusted communication partners. They learn to read the subtle, pre-symbolic communication of their loved one a shift in body posture, a specific movement, a change in breathing and give it meaning (Nafstad & Rødbroe, 2015). They become skilled in the individual's preferred communication mode, whether it is signs on the body, objects, or gestures, and tirelessly work to make daily life comprehensible.

Facilitator of Routines and Predictability

Caregivers are the architects of the daily routine, which serves as a crucial scaffold for understanding time and events. They create tactile calendars, use object schedules, and establish consistent sequences for activities, which provides a sense of security and control for the individual with deaf-blindness (Moller & Danermark, 2007).

The Caregiver as Advocate and Emotional Anchor

Advocate and Liaison

Caregivers are often the strongest advocates for their loved one, navigating complex educational, medical, and social service systems. They translate the individual's needs and preferences to professionals, ensure that IEP goals are relevant, and fight for their right to accessible services and inclusive opportunities (Parker, 2009). They are the keepers of the individual's history, preferences, and strengths, information that is vital for person-centered planning.

Emotional Anchor and Builder of Self-Esteem

The bond between a caregiver and an individual with deaf-blindness is the foundation of emotional security. In a world that can be confusing and frightening, the caregiver provides a safe base through constant, responsive and interaction. They communicate unconditional positive regard, fostering a sense of self-worth and belonging. They create opportunities for success and celebrate small victories, which is essential for building resilience and a

positive self-identity (Dammeyer, 2014).

Challenges Faced by Caregivers

This role is not without significant challenges, including high rates of stress, burnout, and social isolation. The constant demand for vigilance and the emotional labor of interpreting a world without clear feedback can be exhausting. Support for the caregivers is, therefore, not a luxury but a necessity for the well-being of the entire support system.

Conclusion

Creating an accessible environment for a person with deaf-blindness is a complex, ongoing, and deeply human endeavor. It requires moving beyond a compliance-based view of accessibility to a relational, person-centered one. This paper has argued that this environment is co-constructed through the dedicated efforts of a multidisciplinary team of professionals and the unwavering commitment of caregivers. The professional provides the tools, strategies, and external framework, while the caregiver provides the context, consistency, and heart that bring those strategies to life.

True accessibility is realized not in a perfectly adapted room, but in the moment a individual successfully communicates a desire, navigates a new path with confidence, or shares a joke with a friend through touch. These moments are the product of a collaborative ecosystem.

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