

Improving Access to Data on People who are DeafBlind: A Path Forward in the United States

By Megan Conway, Kristen Layton, Peggy Malloy, Jennifer Arnott and Robbin Bull

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Executive Summary

# Introduction

The field of DeafBlindness has long acknowledged the role of conflicting definitions and limited access to data about DeafBlind people as a barrier to service delivery. In 2021 HKNC launched a research project in collaboration with the National Center on Deaf-Blindness and Perkins School for the Blind to compile and analyze literature that illustrates and describes the problem of defining and collecting data about DeafBlind people. We also examined current surveys and registries that collect data about DeafBlind people in the United States. This White Paper outlines the results from our research and identifies actionable next steps for improvement. Our research encompassed a broad spectrum of people who we considered to be DeafBlind, from children to seniors and across populations with varying degrees of combined vision and hearing loss.

This paper describes our findings and lays the foundation for long term outcomes that include: 1) better allocation of resources to meet the needs of specific demographic groups, and 2) improved ability to provide national, state and local government and non-government organizations with data so they can better serve the population of people who are DeafBlind.

# Methodology

We conducted a targeted literature and original data source search from our partner organization collections as well as from national and international databases. The literature and data sources were organized in a shared database that included spreadsheets outlining the use of data and definitions of DeafBlindness. Criteria was established for selecting sources that were most relevant to the guiding questions of the research. The most relevant sources were reviewed and analyzed for themes, sources of data, and terminology use.

The research commenced with four guiding questions:

1. What sources of original data such as national surveys exist for the identification of demographics about people who are DeafBlind in the United States?
2. How is DeafBlind defined in the literature and in original data collection sources in the United States?
3. How many people in the United States of all ages are identified in the literature and in original sources as being DeafBlind?
4. To what extent and how does the literature cite demographic data about DeafBlind people in the United States based on specific demographics such as region, age, gender, race/ethnicity, etc.

The searches included a variety of databases (I.e., PubMed, Samuel P. Hayes Research Library, Google Scholar, and Educational Journals database from ProQuest) using multiple combinations of search terms (I.e., variations on the word, “deafblind” and “dual sensory loss”, names of syndromes associated with DeafBlindness, older adult populations) resulting in the identification of 82 articles and sources. The following criteria was used to identify sources of most relevance to our project: (1) Frequency of citation, (2) Empirical statistical research, (3) Specific conditions, Usher and dual sensory loss in elderly, (4) 2010 or later, (5) U.S. based, and (6) Actual definition of DeafBlindness or Dual Sensory Loss. This process identified 43 articles and sources for closer analysis.

# Findings

Our findings indicate broad discrepancies in how, if at all, the term “DeafBlind” is defined and how, if at all, data is collected about DeafBlind people. It became clear that the terminology and parameters that define the population of people who are DeafBlind varies considerably in the literature and across survey and registry sources. Additionally, demographic and functional impact data on DeafBlind people is inconsistent and inaccessible. These factors compound each other resulting in a lack of empirical evidence about the size, characteristics and service needs of people who are DeafBlind.

Our findings are organized around three central themes: (1) how the term “DeafBlind” and its variations are defined and used, (2) how data about DeafBlind people is collected, referenced and used, and (3) the implications of the intersection between definitions and data. We identify three important implications for discussion:

1. The lack of clear and consistent definitions of DeafBlindness results in disconnected national and international efforts to identify and support DeafBlind people
2. The perception that existing data is unreliable leaves DeafBlind people unidentified and unserved
3. A lack of demographic data and/or easy access to existing data contributes to limited research across diverse populations of people who are DeafBlind.

# Recommendations

We recommend a number of next steps to address the problems identified in the paper, including specific recommendations to (a) raise awareness and improve collaboration (b) address gaps and Inconsistencies in existing national surveys and registries, and (c) advocate for allocation of resources for data collection, research and access to demographic Information. Our recommendations include:

* Disseminate Information About the Need for Consistent Definitions and Data
* Form a Task Force of Stakeholders to Recommend Guidelines for Contextual Use of Definitions
* Create a Network of Researchers and Policy Makers to Improve and Share Empirical Data
* Work with the Census Bureau, Federal Agencies and Organizations to Improve Ease of Access to and Interpretation of Existing Demographic Data
* Work with the Census Bureau, Federal and state agencies and Organizations to Apply Consistent and Comparable Definitions
* Increase Empirical Research that Generates Reliable Data on a Wide Spectrum of the DeafBlind Population
* Expand Existing National Research and Information Databases to Include Searchable Demographic Data on DeafBlind People Across the Lifespan

We conclude that it is important to move beyond describing the problems associated with defining and collecting data about DeafBlind people to taking concrete action. Researchers, policy makers, front line professionals and the DeafBlind community all have a role to play in ensuring that DeafBlind people are visible and accounted for through reliable research and access to comprehensive data.