# Under Identification of Individuals with Deaf-Blindness: Addressing a National Issue

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## Identification of children and youth who are deaf-blind is critical in providing access to appropriate strategies and interventions

**Proper identification** is a critical first step in supporting individuals with [deaf-blindness](https://nationaldb.org/library/list/3) (combined vision and hearing loss) to better access their homes, schools, and communities.

* The [National Deaf-Blind Child Count](https://nationaldb.org/groups/page/11/national-child-count) has remained at approximately 10,000 children since 1995 despite a 23% increase in the overall population (<https://www.census.gov/>).
* Approximately **80%** of individuals who are deaf-blind have **additional and multiple disabilities**, complicating screening, testing, and overall identification.
* **Lack of awareness and understanding** of deaf-blindness may contribute to **85%** of identified child with deaf-blindness being reported **under other disability categories** on OSEP’s Federal IDEA Part B child counts.

### How we can lead change together

**Develop partnerships** between [Deaf-Blind TA Network](https://nationaldb.org/members/list?type=State+Project), state and national level agencies and organizations involved in identification to build or **improve referral systems** to make them **inclusive of deaf-blindness**

* **OSEP’s Deaf-Blind TA Network** consists of a national center (NCDB) and projects serving each state and territory
* NCDB aggregates data from all 48 deaf-blind projects serving U.S. states and territories to identify needs and trends on the[National Deaf-Blind Child Count](https://nationaldb.org/groups/page/11/national-child-count)
* **Identification on the National Deaf-Blind Child Count connects child’s family and educational team to resources and training on deaf-blindness**

### Strategies to address undercount

* Develop partnerships to make **referral systems inclusive of DB**
* Address **IDEA definition** of deaf-blindness
* Develop **guidance for special education administrators** (SEA, LEA)
* Include[**information**](https://nationaldb.org/modules/ohoa/en/overview-of-deaf-blindness-and-instructional-strategies) **in LEND training** and other AUCD programs and information.
* Form **partnerships for research** on prevalence of deaf-blindness
* Policy analysis on factors that may impact **state identification rates**

### Success stories data from pilot project

* Nine states piloted the [Early Identification and Referral Self-Assessment Guide](https://nationaldb.org/pages/show/early-identification-and-referral/early-identification-and-referral-self-assessment-guide) process in 2012
* Pilot data found these states collectively increased identification children with deaf-blindness aged birth to two by 37.6% within five years
* Successful steps by [participating states](https://nationaldb.org/wiki/page/8/960) described on website

### IDEA Part B reporting categories for children on the National Deaf-Blind Child Count

|  |  |
| --- | --- |
| **Reported Category 2017** | **Percentage (N = 9,387)** |
| Multiple Disabilities | 38% |
| Deaf-Blindness | 16% |
| Hearing Impairment | 9% |
| Developmentally Delayed (age 3 to 9) | 6% |
| Other Health Impairment | 6% |
| Intellectual Disability | 5% |
| Visual Impairment | 5% |

\*Categories of Speech Language Impairment, Orthopedic Impairment, Autism, Traumatic Brain Injury, Specific Learning Disability, Emotional Disturbance, and Non-Categorical were each less than 2%.

Source: <https://nationaldb.org/reports/national-child-count-2017/part-b-information#settings-sa>

### Number of Children with Deaf-Blindness reported on National Deaf-Blind Child Count per 1,000 Children in Part C or Part B (averaged for the years 2007-2016)

|  |  |  |  |
| --- | --- | --- | --- |
| **Age Group** | **Number of Children per 1,000 Range Across States** | **National Average****(adjusted for state population size)** | **95% Confidence Interval** |
|  **0–2** | 0.26 **–** 8.37 | 1.73 | 1.53 – 1.92 |
|  **3–5** | 0.41 **–** 4.32 | 1.65 | 1.44 – 1.86 |
|  **6–11** | 0.46 **–** 2.52 | 1.08 | 0.93 – 1.23 |
|  **12–17** | 0.61 **–** 2.13 | 1.08 | 1.00 – 1.16 |
|  **18–21** | 1.35 **–** 11.48 | 4.68 | 4.06 – 5.29 |
|  **0–21** | 0.78 **–** 2.77 | 1.36 | 1.24 – 1.48 |

Note: Puerto Rico was not included in the analysis due to inconsistent reporting. Delaware was not included because its service delivery model differs from the rest of the states.

### Sensory impairment in individuals with profound intellectual disabilities (n=224)

|  |  |  |
| --- | --- | --- |
| **Type of Sensory Impairment** | **Actual Number (%) with Sensory Impairment** | **Number (%) of individuals with unidentified sensory impairment** |
| **Visual impairment** | 86 (38%) | 48 (56%) |
| **Hearing Impairment** | 103 (46%) | 75 (73%) |
| **Deaf-blindness** | 48 (21%) | 40 (83%) |

Fellinger, J., Holzinger, D., Dirmhirn, A., van Dijk, J., & Goldberg, D.  (2009). Failure to detect deaf-blindness in a population of people with intellectual disabilities. *Journal of Intellectual Disability Research, 53*, 874-81.



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