Proper identification is a critical first step in supporting individuals with deaf-blindness (combined vision and hearing loss) to better access their homes, schools, and communities.

- The National Deaf-Blind 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 deafblindness 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, 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
- 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 <u>information</u> 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 <u>Early Identification and</u> Referral Self-Assessment Guide process in 2012
- Pilot data found these states collectively increased identification of children with deaf-blindness aged birth to two by 37.6% within five years
- Successful steps by <u>participating states</u> described on website

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

Julie Durando Partnership for People with Disability, Virginia Commonwealth University Sam Morgan National Center on Deaf-Blindness

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







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

Reported Category 2017	Percentage (N= 9387)
Multiple Disabilities	38%
Deaf-Blindness	16%
Hearing Impairment	9%
Developmentally Delayed (age 3 to 9)	6%
Other Health Impairments	6%
Intellectual Disability	5%
Visual Impairment	5%

<sup>\*</sup>All other categories were less than 2% each. 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	# of Children per 1000 Range Across State	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 and Delaware were not included.

### 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 impairments
Visual Impairment	86 (38%)	48 (56%)
Hearing Impairment	103 (46%)	75 (73%)
Deaf-blindness	48 (21%)	40 (83%)

(Fellinger, Holzinger, Dirmhirn, van Dijk, & Goldberg, 2009)