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An accessible alternative to this document can be found at: http://nationaldb.org/reports/national-child-count-2017

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Introduction

This, the 32nd annual National Child Count of Children and Youth Who Are Deaf-Blind, is the first and longest running registry and knowledge base of children who are deaf-blind in the world. Begun in 1986 on behalf of the U.S. Department of Education, it represents a thirty-plus year collaborative effort between the National Center on Deaf-Blindness (NCDB), its predecessors, and each state and multi-state deaf-blind project throughout the country, as well as projects funded in the Pacific Trust territories, the Virgin Islands, and Puerto Rico. Initially requested by the U.S. Department of Education as an examination of the discrepancy between the National Deaf-Blind Child Count and the Office of Special Education Programs’ (OSEP) annual counts of children and students with disabilities being served under IDEA Part C or Part B, the child count has expanded over time to inform the work of a range of OSEP-funded deaf-blind projects during the ensuing years, including the current national, state, and multi-state technical assistance and dissemination projects.

The National Deaf-Blind Child Count has been collaboratively designed, implemented, and revised to serve as the common vehicle to meet federal grant requirements for both the State and Multi-State Deaf-Blind Technical Assistance Projects and the National Deaf-Blind Technical Assistance Center, as well as serve as a common data collection and reporting mechanism for use across the country. Consistent with the priorities under which NCDB, its predecessors, and the state and multi-state deaf-blind projects are funded, this national count is used to help identify national and state technical assistance needs for children and youth who are deaf-blind, their families, and the service providers and systems that serve them.

The National Deaf-Blind Child Count is conducted each year to supplement OSEP’s Federal IDEA Part C and Part B child counts, which include children as deaf-blind only when deaf-blindness is their single disability. In contrast to OSEP’s Part C and Part B child counts, the National Deaf-Blind Child Count data is collected for children whose disability is solely deaf-blindness, as well as those who are identified as deaf-blind and have additional disabilities. This is a critical distinction given that over 85% (86.6%) of the children and youth on the National Deaf-Blind Child Count have one or more additional disabilities. Consequently, a majority of children who are deaf-blind or have deaf-blind intervention needs are not identified as such on OSEP’s IDEA Part C and Part B child counts.

Between December 1, 2016 and December 1, 2017, state and multi-state deaf-blind projects reported 10,950 children and youth were eligible to receive services. On December 1, 2017, state and multi-state deaf-blind projects reported that 10,435 children and youth were eligible to receive services. Of these, 10,000 were both eligible to receive deaf-blind project services and were being served through either Part C or Part B of IDEA. Therefore, a total of 10,000 children and youth are included on the December 1, 2017 Deaf-Blind Child Count.

Across the United States, 613 infants (birth-2) and 9,301 children and young adults (3-21) were identified and reported as deaf-blind by the state and multi-state deaf-blind projects on the December 1, 2017 Deaf-Blind Child Count. An additional 86 students were reported by those projects, who by their respective state’s legislation or regulation, continue to provide services through the end of the school year in which the student turns 22 years of age. These individuals make up the total of 10,000 infants, children, and young adults
identified as deaf-blind by the state and multi-state deaf-blind projects. This figure represents a slight increase from the previous year.

In contrast, the U.S. Department of Education (2017a) reports that 1,278 students (3-21) were identified as deaf-blind on OSEP’s IDEA Part B "Snapshot" Child Count. Due to the non-categorical nature of Part C, no infants or toddlers are reported as deaf-blind as they are all reported as developmentally delayed or at-risk by their state Part C lead agencies (2017b). This discrepancy of more than 80% between Part B and Part C reporting of children and youth who are deaf-blind and the National Deaf-Blind Child Count is significant. State and multi-state deaf-blind project directors consistently indicate that most Part C lead agencies and State Education Agencies report their children and students with deaf-blindness as being developmentally delayed, multiply disabled, and/or visually impaired or hearing impaired, rather than identifying them as deaf-blind. Concerns about the under-identification of deaf-blindness and its resulting unique intervention requirements have been a consistent problem and one that often results in a lack of or delay in receiving appropriate intervention and instruction critical to children’s early development (Herbster, 2015; Mueller, 2006; Purvis & Schalock, 2014). The opportunity for early identification, intervention, and provision of instructional services aimed at the unique needs of young children and students who are deaf-blind is a critical component that should not be lost.

In reviewing the child count data submitted over the years, it is notable that children who are deaf-blind are highly diverse. Clearly, children who are deaf-blind are as varied as the number reported, and the nature and extent of deaf-blindness in children is often misunderstood (Malloy & Killoran, 2007; McCormick, 2015; Schalock, 2017). These children represent one of the lowest incidence yet most diverse group of learners receiving early intervention and special education services. They are an extremely heterogeneous group whose sensory losses are often accompanied by additional physical or cognitive disabilities, complex medical needs, and/or behavior challenges.

Data Elements in the National Deaf-Blind Child Count

Throughout the history of the child count, NCDB and its predecessors have continuously revised the child count language and reporting elements to a) remain current with IDEA Section 618 Part C and Part B data requirements, b) ease the data collection burden of the projects, and c) increase process and cost efficiencies.

Current data elements target both IDEA Section 618 requirements and the collection of information to guide state-specific and national technical assistance. Existing data elements have been broken out into specific Part B and Part C elements using Section 618 language. Reported data elements that are consistent with the IDEA mandated child counts include:
2017 National Deaf-Blind Child Count Summary (Ages Birth – 21)

- Race/Ethnicity
- Part B and C Category Codes
- Early Intervention Setting (Birth through 2)
- Educational Setting (3-5 and 6-21)
- Participation in Statewide Assessments
- Part CExiting Status (Birth through 2)
- Part B Exiting Status (3-21)

Data elements have also been included to assist in developing state and national technical assistance initiatives (e.g., collection of demographic and needs assessment information). These include:

- Gender
- Etiology
- Documented Vision Loss
- Cortical Vision Impairment
- Documented Hearing Loss
- Central Auditory Processing Disorder
- Auditory Neuropathy
- Cochlear Implants
- Other Impairments or Conditions
- Living Setting
- Intervener Services
- Use of Corrective Lenses, Listening Devices, and/or Assistive Technology

**Considerations for the Reader**

When reading the information that follows, the reader should note that:

- Although the *IDEA* definition is used as the common definition of deaf-blindness, each state or multi-state deaf-blind project has the discretion of establishing criteria for their own project services. This definition was modified for birth-2 to reflect Part C Early Intervention program services and infant-toddler outcomes.

- The National Deaf-Blind Child Count is collected in a timeline similar to *IDEA* Section 618 data requirements. A point-in-time “snap shot” is used to reflect those infants, young children, and students identified and eligible for services from state and multi-state deaf-blind projects on December 1 of each year. Thus, in many instances, projects serve more infants, young children, and students over the course of the year than are reported on December 1.

- Where crossover exists, the language and reporting elements used in the National Deaf-Blind Child Count are consistent with those found in Section 618 of *IDEA*. 
The National Deaf-Blind Child Count data presented are based on aggregate data reported by each state and multi-state deaf-blind project. While the aggregated counts provide a national perspective, there is substantial variability in the individual state project data reports.

### Overall Population Demographics

The total December 1, 2017 Deaf-Blind “Snap Shot” count increased to 10,000; a gain of 365 from 2016. Overall, the total number of children and youth served during the year also increased from 10,749 to 10,950.

While 1,163 children and youth exited from state and multi-state project eligibility, 1,380 were added through child find and referral efforts. This indicates an almost 25% turnover in the child counts of the states.

Newly identified children and youth spanned the full age range of birth through 21. Nearly half (48.8%) were birth through 5 years of age. Conversely, over half (55.4%) of the children and youth exiting the child count were ages 18 and over. Other than age, these newly identified individuals have demographics that are consistent with the overall population of children and youth who are deaf-blind.

The distribution of children/youth across age groups has remained relatively stable over the past five years. Since 2013, the number of children from birth to 2 years of age increased from 552 to 613 in 2017. Since 2013 the number of children aged 3 to 5 has increased only slightly, from 1,197 in 2013 to 1,222 in 2017. The number of children and youth aged 6 to 17 increased from 6,116 to 6,545. The number of those 18 years of age and older also increased from 1,561 to 1,621.

The overall distribution of children and youth by race and ethnicity continues to slowly evolve, reflecting broader population changes. The racial/ethnic makeup of the children and youth who are deaf-blind has remained fairly consistent over the past 5 years. There have been slight changes, but nothing significant. For example, the percentage of the population identified as white decreased from 54.4% to 53.6%. The percentage of the population identified as black or African American dipped slightly from 14.4% to 14.3%. The percentage identified as Latino or Hispanic showed a similar small dip from 20.4% to 19.6%. All of the other categories experienced small increases.

The racial/ethnic makeup of the children and youth on the National Deaf-Blind Child Count mirrors fairly well the overall US population. Generally, children and youth who are white are slightly under-represented, while children and youth who are Black/African American or Latino/Hispanic are slightly over-represented.

The distribution of children and youth by gender has remained very stable over time, with about 54% of children and youth being male and 46% female.

The apparent under-identification and referral to state and multi-state deaf-blind projects of very young infants and children remains an important issue. Infants and toddlers benefit greatly from having access to expertise in deaf-blindness. They require appropriate services that address the impacts of dual sensory impairments. Further, parents and families of these infants and toddlers can benefit from supports established within states. Without such early identification and referral to state and multi-state deaf-
blind programs, access to needed services and supports is compromised. Trends demonstrate that what has historically been one of the lowest incidence, yet most heterogeneous populations, continues to become even more so. As our nation’s population becomes more diverse ethnically, racially, culturally, and even linguistically, our national, state, and local systems must continue to adapt to provide effective services to these children and youth and their families.

**State Child Count Totals**

<table>
<thead>
<tr>
<th>State</th>
<th>Total Number Served by State During Year</th>
<th>Number Eligible to Receive Project Services on 12-1-2017 Regardless of Part C or Part B Status</th>
<th>12-1-17 Snap Shot: Number on Child Count (1)</th>
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# 2017 National Deaf-Blind Child Count Summary (Ages Birth – 21)

<table>
<thead>
<tr>
<th>State</th>
<th>Total Number Served by State During Year</th>
<th>Number Eligible to Receive Project Services on 12-1-2017 Regardless of Part C or Part B Status</th>
<th>12-1-17 Snap Shot: Number on Child Count <em>(1)</em></th>
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<tbody>
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<td><strong>10435</strong></td>
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*(1) December 1 snap shot based on children/youth in Part C or Part B and eligible for project services.*
## Age of Child

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<tr>
<th>State</th>
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<th>3 thru 5</th>
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<th>12 thru 17</th>
<th>18 thru 21</th>
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### Documented Hearing and Vision Loss

The overall distribution of degree of vision loss has remained relatively consistent over time. A total of 7,853 or just under 80% of the children and youth were identified as having low vision, being legally blind, or having a documented functional vision loss in 2017. A total of 497, about 5% of the population, is totally blind. These distributions have remained fairly consistent over the past five years, fluctuating 1 to 3% during this time period. There has been a slight increase in the percentage of children and youth with low vision and a documented functional vision loss. The percentage of children who are legally blind has declined.

The number of children and youth who have an identified cortical vision impairment has grown slightly over the past five years from 2,816 in 2013 to 2,906 in 2017 and represents about 30% of the population.

The documented degree of hearing loss is more evenly distributed from mild to profound. A total of 1,999 children and youth have a profound hearing loss and make up the largest group at nearly 20%. The number of children with a documented functional hearing loss (1,254) is about equal to the number of children and youth with a mild hearing loss (1,332). These distributions have remained very consistent over the past five years, fluctuating only 1 to 2%. The percentage of children/youth identified as needing further hearing testing has fluctuated from 8.3% to 7.2% over the past five years.

Relatively few children and youth have been identified as having a central auditory processing disorder (549) or auditory neuropathy (531). In both cases, these numbers represent less than 6% of the population.

The number of children identified as having received cochlear implants has increased from 914 in 2013 (9.7%) to 1,098 in 2017 (11.0%). This increase is true for all ages, from infants to young adults.

In 2017, less than half of the children and youth made use of corrective lenses (42.3%), assistive listening devices (48.1%), or additional assistive technology (48.8%). While there has been a significant increase over the past five years in the percentage of children and youth with corrective lenses from 37.8% to 42.3% and assistive listening devices from 43.6% to 48.4%, there has been a small decrease in the use of other assistive technologies from 45.0% to 44.0%.

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The broad range and combinations of vision and hearing loss of the children and youth on the National Deaf-Blind Child Count provide evidence of the heterogeneous nature of this population and their needs. Only about 1% of the population has a profound hearing loss and is totally blind. The other 99% have some residual hearing or vision.

While the number of children and youth needing further vision and or hearing testing has decreased over time, there is still a need for increased access to pediatric audiologists and optometrists. The number of children and youth who have been identified as having a cortical vision impairment (30%) indicate continued work in this area is crucial.

The number of children/youth with cochlear implants has continued to grow over the past five years. This increase may require significant program development within the Deaf-Blind Network to provide appropriate supports for this growing population.

Assistive technology plays an important role in the lives of children and youth who are deaf-blind especially those with more intensive support needs. Overall, the percentage of children and youth that use of assistive technologies has remained fairly constant over the past five years at about 45%. However, only about 25% of children and youth with no additional disabilities are reported to use additional assistive technologies while over 50% of children with four or more additional disabilities use additional assistive technologies.
# Primary Classification of Vision Impairment

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### Etiologies

Over 70 specific etiologies are identified in the 2017 National Deaf-Blind Child Count. Some are exceedingly rare, with less than five cases. Others are much more prevalent. There are 13 etiologies with at least 100 cases, and one—Cornelia de Lange syndrome—with 99.

Complications from prematurity continues to be the most commonly identified etiology. The prevalence of CHARGE syndrome continues to increase. In 2017 there were 933 children and youth identified as having CHARGE syndrome. While still relatively rare, the prevalence of children with Stickler syndrome and Dandy Walker syndrome has also increased. About 19.0% of the children and youth have no determined etiology.

Overall, the total number of children and youth identified with a prenatal congenital or postnatal non-congenital etiology has declined from 2,732 to 2,551 over the past five years, while the number with hereditary syndromes and disorders has increased from 3,945 to 4,482. Hereditary syndromes and disorders now account for 44.8% of all identified etiologies. Prenatal congenital complications account for 13.9% of identified etiologies and postnatal non-congenital complications account for 11.6% of identified etiologies. Complications from prematurity account for 10.5% of identified etiologies and 19.2% of the children and youth had no identified etiology at the time data was collected.

Congenital Rubella Syndrome (CRS), which has long been associated with the development of the deaf-blind technical assistance system, is no longer a prevalent etiology. In 2017, there were 41 individuals whose etiology was identified as CRS, down from 89 in 2010. Over 75% of these individuals are over 10 years of age and over 50% are 15 years of age or older.

The heterogeneous nature of the population cannot be overstated. The etiologies or causes of deaf-blindness bring unique issues and challenges. Some are relatively more common, such as CHARGE syndrome, Down syndrome, Usher syndrome, and Cytomegalovirus. Some are very rare, with less than five individuals reported nationally, such as Batten disease, Prader-Willi, and Kearns-Sayre syndrome.
2017 National Deaf-Blind Child Count Summary (Ages Birth – 21)

**Primary Identified Etiology**

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**Prenatal/Congenital Complications**

| Cytomegalovirus (CMV)                                  | 292   |
| Hydrocephaly                                           | 214   |
| Microcephaly                                           | 206   |
| OTHER: Pre-Natal/Congenital Complications               | 679   |

**Postnatal/Non-Congenital**

| Asphyxia                                               | 194   |
| Severe Head Injury                                     | 159   |
| Meningitis                                             | 137   |
| OTHER: Post-Natal/Non-Congenital                       | 670   |

**Complication of Prematurity**

|                                                     | 1,047 |

**No Determination of Etiology**

|                                                     | 1,920 |

More detail about etiology is provided in the following four tables.
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# 2017 National Deaf-Blind Child Count Summary (Ages Birth – 21)

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### Additional Disabilities

The nature and prevalence of additional challenges faced by the children and youth on the National Deaf-Blind Child Count have remained relatively stable during the past 5 years. Approximately 87% have been identified as having one or more additional disabilities. Most common are cognitive impairments, orthopedic impairments, and complex health care needs.

The percentage of children and youth experiencing orthopedic or physical challenges
has fluctuated between 59% and 61% during this time frame. Similarly, the percentage of children and youth experiencing intellectual/cognitive challenges has fluctuated between 65% and 68%. Slightly fewer children and youth have experienced complex health care needs, fluctuating between 51% and 53%.

The number of additional disabilities experienced by children and youth has increased over time. In 2005, just 13.1% of the children and youth on the count had four or more additional disabilities. In 2017, nearly 43% were reported as having four or more additional disabilities.

The population continues to be diverse in terms of experiencing additional disabilities. Almost 90% have one or more additional disabilities and over 40% have four or more. The increasing level of complexity in the needs and challenges faced by this population requires continued evolution and adaptation in national, state, and local systems to provide needed services effectively. Conversely, more children and youth are also being identified with no additional disabilities. This group of children and youth has increased from 10.4% to 13.4% of the overall population over the past five years, requiring additional focus at state and national levels.
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Part C Information

Because Part C is non-categorical, the vast majority of infants and toddlers are identified as developmentally delayed. Some states provide an “at risk” category. About 18% of infants and toddlers were identified as at risk.

Almost all infants and toddlers receive intervention services in the home.

The apparent continued under-identification and referral to deaf-blind programs of very young children remains an important need. Infants and toddlers greatly benefit from having access to expertise in deaf-blindness and must receive appropriate services that address the impact of dual sensory impairments. Further, parents and families of these infants and toddlers can benefit from supports established within states. Without such early identification and referral to state deaf-blind programs, access to needed services and supports is compromised.

As Part C agencies continue to appropriately serve children and families, there are increased needs for early interventionists with knowledge of deaf-blind intervention and instruction.

IDEA Part C Reported Category

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**National Total**: 550 && 34 && 15 && 14 && 613
Part B Information

The distribution of Part B Disability Categories has remained fairly stable over the past 7 years. No significant shifts have occurred. Over two-thirds of all the children and youth in Part B have one of four designations: Multiple Disability (37.7%), Deaf-Blind (15.8%), Hearing Impaired (9.4%), or Visually Impaired (5.1%). This distribution has remained essentially unchanged for the past five years.

The percentage of young children, aged 3 to 5, educated in a regular early childhood education setting some portion of the day, has doubled in the past decade from less than 15% to 30%. Over 60% of school-age children and youth in special education are being served at least a portion of their day in a regular classroom in their local school. This is consistent across the age span.

Over one quarter (26.1%) of children and youth on the 2017 National Deaf-Blind Child Count participate in the regular curriculum as indicated by participating in statewide assessments tied to regular grade level standards. This is up slightly from 2016.

While educational placement does not determine access to the regular curriculum, nearly 78% of students taking state assessments tied to regular grade level standards were in a regular classroom some portion of their day.

The continued trend toward educational placement in inclusive settings, especially at the pre-school level, is significant and positive for children and families. This trend has profound implications on the need for information, resources, and access to expertise in deaf-blindness being available at a local level. Concurrently, as schools and Part C agencies continue to appropriately place and serve children locally, there are increased needs for more interventionists and teachers with knowledge of deaf-blind intervention and instruction, and for individualized supports, including the provision of intervener services.

While access to the general curriculum and graduation from high school has improved for the population of children and youth who are deaf-blind, significant efforts are needed to expand these opportunities.
# IDEA Part B Reported Category (Part 1 of 2)

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Educational Supports

Data on children and youth receiving intervener services was collected on a pilot basis during the 2014 child count, with some state deaf-blind projects collecting the information. A total of 394 children and youth were reported as receiving intervener services during that year. The category was fully implemented in 2015, during which 587 children and youth were reported as receiving intervener services. This year (2017), 713 children and youth were reported as receiving intervener services.

Interveners are key players in providing access to a child or youth who is deaf-blind. They provide access to information, the environment, communication, and conceptual learning. While it is encouraging to see that 713 children and youth are receiving intervener services, it is also discouraging that this accounts for only 7% of the population. Continued efforts are needed to implement the 2012 Intervener Services Recommendations.

Intervener Services

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### Living Setting

The vast majority of children and youth live at home with their parents or extended family (92.9%). This percentage has gone up slightly over the past five years. Fewer children and youth are living with foster parents, in state or private residential facilities, or in group homes or apartments.

Given that almost all children and youth who are deaf-blind live in a home setting, providing supports to families (nuclear, extended, and foster) is critical. Supports that include access to parent networks and leadership/self-advocacy skills training are important components of the umbrella of services needed for children who are deaf-blind and their families.
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### Exiting Information

The vast majority of children who exit Part C are eligible for Part B (91.4%). This percentage has remained relatively constant over the past five years, varying between 90% and 93%. The balance have moved out of state, been withdrawn by parents, were not able to be contacted, or died.

An analysis to determine whether kids are “lost” in the transition from Part C to Part B revealed that about 15% of two-year-old children eligible for Part B on the 2016 National Deaf-Blind Child Count were not included on the 2017 child count as three year olds. Conversely, over one third (34.6%) of the 3-year-old children on the 2017 child count were not included on the 2016 child count as 2 year olds. Clearly, the transition from Part C to Part B represents a major child find challenge.

Children and youth exit Part B for a number of reasons. They graduate, age out, transfer to regular education, drop out, or die. From 2013 to 2017, there has been a decrease in the number of youth graduating with a regular diploma, from 199 to 153. This has been accompanied by an increase in the number of youth who have aged-out from 192 to 231.

Ensuring seamless transition between Part C and Part B is critical for maintaining appropriate services for children as they enter preschool. The number of children who seem to be “lost” in this transition warrants attention.

While access to the general curriculum and graduation from high school has improved for the population of children and youth who are deaf-blind, significant efforts are needed to expand these opportunities.

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The need for post-secondary education or employment has important implications for the continued development of effective post-secondary supports for students who are exiting Part B every year, whether through having received a diploma or certificate, simply aging out, or transitioning to adult services. The growing number of youth who drop out of school also has important implications for effective educational programming and the continued development of effective post-secondary supports.

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2017 National Deaf-Blind Child Count Summary (Ages Birth – 21)


**Contact Information**

Questions may be directed to Robbin Bull at bullr@wou.edu.

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