

**PENNSYLVANIA DEPARTMENT OF EDUCATION  
BUREAU OF SPECIAL EDUCATION**

December 2007

**SUBJECT:** 2007 Annual National Deafblind Census

**TO:** School District Special Education Directors  
Intermediate Unit Special Education Directors  
Administrators of Mutually Agreed Upon Written Arrangements (MAWA)  
Administrators of Approved Private Schools (APS)  
Superintendent, Scranton State School for the Deaf (SSSD)  
Administrators of Charter Schools  
Directors of County Offices of Mental Health/Mental Retardation (MH/MR)  
Directors of County Offices of ARC

**FROM:** John J. Tommasini  
Director

The Bureau of Special Education is currently conducting, through the Pennsylvania Deafblind Project, the data collection for all infants, toddlers, and children (birth through age 21) who are deafblind or at risk for deafblindness and were enrolled in special education programs and services or early intervention services on December 1, 2007. This process is also known as the Annual National Deafblind Census and is required by the U.S. Department of Education, Office of Special Education Programs (OSEP).

OSEP uses the Annual National Deafblind Census to allocate federal funds to all states for educating infants, toddlers, and children with dual sensory impairment (deafblindness) and those at risk for dual sensory impairments. Not reporting or under reporting the Annual National Deafblind Census will jeopardize funding for technical assistance training and to special education programs or early intervention service providers for infants, toddlers, and preschoolers with deafblindness. It is crucial for you to support this process, and ensure that all eligible infants, toddlers, and children with deafblindness are being reported accurately. In Pennsylvania, Hand in Hand is the project responsible for providing training and technical assistance related to deafblindness.

Please review the following procedures for the December 1, 2007, Annual National Deafblind Census Report:

1. School districts, charter schools, MAWA agencies, and early intervention service providers will submit the required data to the Hand in Hand on the provided Deafblind Census forms **before March 10, 2008**, for eligible children for whom they are legally responsible for the provision of special education programs and services or early intervention services.

2. School districts and MAWA agencies that placed eligible children in an APS or SSSD will work with the pertinent school to verify, update, and submit the required data on census forms for these children to Hand in Hand Project **before March 10, 2008.**
3. Hand in Hand will verify each Deafblind Census report.
4. Hand in Hand will compile the National Deafblind Census final report and submit it to the National Consortium on Deaf-Blindness(NCDB) for inclusion in the National Deaf-Blind Summary.

Attached please find the December 1, 2007, Deafblind Census forms with technical instructions. If you have questions regarding the procedures, please contact Juli Baumgarner, by phone at 800-446-5607, extension 6876, or by email [jbaumgarner@pattan.net](mailto:jbaumgarner@pattan.net). The Deafblind Census form and numeric code list may also be downloaded from the Deafblind Project's section of the Pennsylvania Training and Technical Assistance (PaTTAN) web page at <http://www.pattan.net/teachlead/Deafblind.aspx>.

Please note:

- If your school district, school, or agency has previously identified a child for the deafblind census, a child-specific form, printed on yellow paper, is sent to the current school district, school, or agency contact, in order to be updated.
- If your school district, school, or agency is unsure whether a specific child has been previously identified or who the current contact is, contact Juli Baumgarner (see information above).
- If your school district, school, or agency has no one to identify, please file the blank form for future use. You may identify new children at any time of the year. Simply complete the blank form and mail to Hand in Hand.

CC: Maureen Cronin, Department of Public Welfare

## DECEMBER 1, 2007 DEAFBLIND CENSUS REPORTING FORM

### **Notice:**

The data collection for all infants, toddlers, and children with deafblindness who are enrolled in special education and services is currently being conducted by the Bureau of Special Education through the Pennsylvania Deafblind Project. Please work with those responsible for providing special education programs and services to verify, update, and submit the required data for each eligible child. Please note that due to changes in required data collection procedures, this year's Reporting Form and categories are different than the previous Reporting Form and categories. If you have questions, contact Juli Baumgarner at (800)446-5607, ext. 6876 or e-mail: [jbaumgarner@pattan.net](mailto:jbaumgarner@pattan.net).

### **Federal Definitions:**

The term "children with deafblindness" means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities.

The term "infants and toddlers with deafblindness" means individuals from birth through age two who are experiencing developmental delays in hearing and vision, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in hearing and vision, or are at risk of having substantial developmental delays in hearing and vision if early intervention services are not provided.

### **Information:**

Throughout the year, the Deafblind Project automatically sends Information Updates and other relevant materials to the family of the identified child, the contact person listed, the teacher listed, to each intermediate unit director, school district special education supervisor, early intervention program director, MAWA holder director, and county MH/MR offices, unless otherwise notified. Also check for information, resources, and workshops on the Deafblind Project section of the Pennsylvania Training and Technical Assistance (PaTTAN) web page (<http://www.pattan.net/teachlead.Deafblind.aspx>).

**2007 Deafblind Census Reporting Form**

Please complete and return to:

PaTTAN/Deafblind Census Coordinator; 6340 Flank Drive; Harrisburg PA 17112-2764.

**Directions: Please review for accuracy, complete missing information, and update codes. Cross out and correct any incorrect information. Write changes on the same page.**

Today's Date: \_\_\_\_\_

Status of this Individual's Report (please check one):

- |  |  |                                      |
|--|--|--------------------------------------|
| <input type="checkbox"/> Newly identified since 1/06     | <input type="checkbox"/> No longer eligible: Testing shows no/minimal hearing loss | <input type="checkbox"/> Deceased    |
| <input type="checkbox"/> Moved into state since 1/06     | <input type="checkbox"/> No longer eligible: Testing shows no/minimal vision loss  | <input type="checkbox"/> 999 Unknown |
| <input type="checkbox"/> Moved out of state              | <input type="checkbox"/> No longer eligible: No hearing or vision loss             |                                      |
| <input type="checkbox"/> Previously identified on census | <input type="checkbox"/> No longer eligible: Over age 22                           |                                      |

**Part I: Information about individual with deafblindness**

Name First: \_\_\_\_\_ Last: \_\_\_\_\_

Date of Birth (MM/DD/YYYY)      /      /      Gender:  Male  Female

Race/Ethnicity (select the ONE that best describes the individual's race/ethnicity):

- |   |  |
|---|--|
| <input type="radio"/> 1 American Indian or Alaskan Native | <input type="radio"/> 4 Hispanic             |
| <input type="radio"/> 2 Asian or Pacific Islander         | <input type="radio"/> 5 White (not Hispanic) |
| <input type="radio"/> 3 Black (not Hispanic)              |  |

Living Setting (Select the ONE setting that best describes where the individual resides the majority of the year.):

- |  |   |  |
|--|---|--|
| <input type="radio"/> 1 Home: Birth/Adoptive Parents | <input type="radio"/> 5 Private Residential Facility          | <input type="radio"/> 9 Pediatric Nursing Home |
| <input type="radio"/> 2 Home: Extended Family        | <input type="radio"/> 6 Group Home (less than six residents)  | <input type="radio"/> 555 Other:               |
| <input type="radio"/> 3 Home: Foster Parents         | <input type="radio"/> 7 Group Home (six or more residents)    |  |
| <input type="radio"/> 4 State Residential Facility   | <input type="radio"/> 8 Apartment (with non-family person(s)) |  |

Parent/Guardian Name 1 First: \_\_\_\_\_ Last: \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP Code: \_\_\_\_\_

Telephone (with Area Code): \_\_\_\_\_ County of Residence: \_\_\_\_\_

Parent/Guardian Name 2 First: \_\_\_\_\_ Last: \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP Code: \_\_\_\_\_

Telephone (with Area Code): \_\_\_\_\_ County of Residence: \_\_\_\_\_

**Part II: Individual's Medical Background/Handicapping Conditions**

Primary Classification of Visual Impairment (select the ONE that best describes the primary classification of the individual's visual impairment):

- |   |  |   |
|---|--|---|
| <input type="radio"/> 1 Low Vision            | <input type="radio"/> 4 Totally Blind              | <input type="radio"/> 9 Documented Functional Vision Loss |
| <input type="radio"/> 2 Legally Blind         | <input type="radio"/> 6 Diagnosed Progressive Loss |   |
| <input type="radio"/> 3 Light Perception Only | <input type="radio"/> 7 Further Testing Needed     |   |

Cortical Vision Impairment?  Yes  No

Primary Classification of Auditory Impairment (select the ONE that best describes the primary classification of the individual's auditory impairment):

- |   |  |  |
|---|--|--|
| <input type="radio"/> 1 Mild              | <input type="radio"/> 4 Severe                     | <input type="radio"/> 7 Further Testing Needed             |
| <input type="radio"/> 2 Moderate          | <input type="radio"/> 5 Profound                   | <input type="radio"/> 8 XXX                                |
| <input type="radio"/> 3 Moderately Severe | <input type="radio"/> 6 Diagnosed Progressive Loss | <input type="radio"/> 9 Documented Functional Hearing Loss |

Central Auditory Processing Disorder (CAPD)?  Yes  No

Cochlear Implant?  Yes  NoAuditory Neuropathy?  Yes  No**Other Impairments** (indicate YES or NO for

Physical Impairments  Yes  No    Complex Health Care Needs  Yes  No  
 Cognitive Impairments  Yes  No    Communication Speech/Lang  Yes  No  
 Behavioral Disorder  Yes  No    Other: \_\_\_\_\_  Yes  No

**Etiology** (please indicate the ONE etiology from the list below that best describes the primary etiology of the individual's primary disability. Please indicate "Other" if none of the listed etiologies are the primary disability):

## Hereditary/Chromosomal Syndromes and Disorders

- |  |  |
|--|--|
| <input type="radio"/> 101 Aicardi syndrome                               | <input type="radio"/> 130 Marshall syndrome                            |
| <input type="radio"/> 102 Alport syndrome                                | <input type="radio"/> 131 Maroteaux-Lamy syndrome (MPS VI)             |
| <input type="radio"/> 103 Alstrom syndrome                               | <input type="radio"/> 132 Moebius syndrome                             |
| <input type="radio"/> 104 Apert syndrome (Acrocephalosyndactyly, Type I) | <input type="radio"/> 133 Monosomy Tenp                                |
| <input type="radio"/> 105 Bardet-Biedl syndrome (Laurence Moon-Biedl)    | <input type="radio"/> 134 Morquio syndrome (MPS IV-B)                  |
| <input type="radio"/> 106 Batten disease                                 | <input type="radio"/> 135 NF One - Neurofibromatosis                   |
| <input type="radio"/> 107 CHARGE association                             | <input type="radio"/> 136 NF Two- Bilateral Acoustic Neurofibromatosis |
| <input type="radio"/> 108 Chromosome eighteen, Ring eighteen             | <input type="radio"/> 137 Norrie disease                               |
| <input type="radio"/> 109 Cockayne syndrome                              | <input type="radio"/> 138 Optico-Cochleo-Dentate Degeneration          |
| <input type="radio"/> 110 Cogan syndrome                                 | <input type="radio"/> 139 Pfeiffer syndrome                            |
| <input type="radio"/> 111 Cornelia de Lange                              | <input type="radio"/> 140 Prader-Willi                                 |
| <input type="radio"/> 112 Cri du chat syndrome (Chromosome 5p-Syndrome)  | <input type="radio"/> 141 Pierre-Robin syndrome                        |
| <input type="radio"/> 113 Crigler-Najjar syndrome                        | <input type="radio"/> 142 Refsum syndrome                              |
| <input type="radio"/> 114 Crouzon syndrome (Craniofacial Dysostosis)     | <input type="radio"/> 143 Scheie syndrome (MPS I-S)                    |
| <input type="radio"/> 115 Dandy Walker syndrome                          | <input type="radio"/> 144 Smith-Lemli-Optiz (SLO) syndrome             |
| <input type="radio"/> 116 Down syndrome (Trisomy Twenty-one)             | <input type="radio"/> 145 Stickler syndrome                            |
| <input type="radio"/> 117 Goldenhar syndrome                             | <input type="radio"/> 146 Sturge-Weber syndrome                        |
| <input type="radio"/> 118 Hand-Schuller-Christian (Histiocytosis X)      | <input type="radio"/> 147 Treacher Collins syndrome                    |
| <input type="radio"/> 119 Hallgren syndrome                              | <input type="radio"/> 148 Trisomy thirteen (Patau syndrome)            |
| <input type="radio"/> 120 Herpes-Zoster (or Hunt)                        | <input type="radio"/> 149 Trisomy eighteen (Edwards syndrome)          |
| <input type="radio"/> 121 Hunter syndrome (MPSII)                        | <input type="radio"/> 150 Turner syndrome                              |
| <input type="radio"/> 122 Hurler syndrome (MPS I-H)                      | <input type="radio"/> 151 Usher I syndrome                             |
| <input type="radio"/> 123 Kearns-Sayre syndrome                          | <input type="radio"/> 152 Usher II syndrome                            |
| <input type="radio"/> 124 Klippel-Feil sequence                          | <input type="radio"/> 153 Usher III syndrome                           |
| <input type="radio"/> 125 Klippel-Trenaunay-Weber syndrome               | <input type="radio"/> 154 Vogt-Koyanagi-Harada syndrome                |
| <input type="radio"/> 126 Kniest Dysplasia                               | <input type="radio"/> 155 Waardenburg syndrome                         |
| <input type="radio"/> 127 Leber congenital amaurosis                     | <input type="radio"/> 156 Wildervanck syndrome                         |
| <input type="radio"/> 128 Leigh disease                                  | <input type="radio"/> 157 Wolf-Hirschhorn syndrome (Trisomy 4p)        |
| <input type="radio"/> 129 Marfan syndrome                                | <input type="radio"/> 199 Other  |

## Pre-Natal/Congenital Complications

- |   |  |   |
|---|--|---|
| <input type="radio"/> 201 Congenital Rubella Syndrome | <input type="radio"/> 205 Fetal Alcohol Syndrome | <input type="radio"/> 209 Neonatal Herpes Simples (HSV) |
| <input type="radio"/> 202 Congenital Syphilis         | <input type="radio"/> 206 Hydrocephaly           | <input type="radio"/> 299 Other                         |
| <input type="radio"/> 203 Congenital Toxoplasmosis    | <input type="radio"/> 207 Maternal Drug Use      |   |
| <input type="radio"/> 204 Cytomegalovirus (CMV)       | <input type="radio"/> 208 Microcephaly           |   |

## Post-Natal/Non-Congenital Complications

- |   |  |  |                                 |
|---|--|--|---------------------------------|
| <input type="radio"/> 301 Asphyxia                            | <input type="radio"/> 304 Infections         | <input type="radio"/> 307 Stroke             | <input type="radio"/> 399 Other |
| <input type="radio"/> 302 Direct Trauma to the eye and/or ear | <input type="radio"/> 305 Meningitis         | <input type="radio"/> 308 Tumors             |                                 |
| <input type="radio"/> 303 Encephalitis                        | <input type="radio"/> 306 Severe Head Injury | <input type="radio"/> 309 Chemically Induced |                                 |

## Related to Prematurity

 401 Complications of Prematurity

## Undiagnosed

 501 No Determination of Etiology**Part III: IDEA**

**Funding Category** (please indicate the funding category under which the individual was receiving services on December 1, 2007):

- 1 IDEA Part B (three through twenty-one years)  3 Not reported under Part B or Part C  
 2 IDEA Part C (birth through two years)

## -----Part C-----

**Special Education Status/Part C Exiting** (please indicate the ONE code that best describes the individual's special education program status):

- 0 In a Part C early intervention program  6 Deceased  
 1 Completion of IFSP  7 Moved out of state  
 2 Eligible for IDEA, Part B  8 Withdrawal by parent/guardian  
 3 Not eligible for Pt B, referral to other program  9 Could not contact parent  
 4 Not eligible for Pt B, exit w/no referrals  10 No longer receives EI, receiving state DB project svcs  
 5 Part B eligibility not determined  11 No longer meets DB criteria

**Part C Category Code** (please indicate the primary category code under which the individual was reported on the Part C, IDEA Child Count - select only ONE. See attached GUIDELINE for additional information, if needed.):

- 1 At-risk  9 Other Health Impairment  
 2 Developmentally Delayed  10 Specific Learning Disability  
 3 Mental Retardation  11 Deaf-blindness  
 4 Hearing Impairment (includes deafness)  12 Multiple Disabilities  
 5 Speech or Language Impairment  13 Autism  
 6 Visual Impairment (includes blindness)  14 Traumatic Brain Injury  
 7 Emotional Disturbance  888 Not Reported under Part C of IDEA  
 8 Orthopedic Impairment

## -----Part B-----

**Special Education Status/Part B Exiting** (please indicate the ONE code that best describes the individual's special education program status):

- 0 In Special Education Program  5 Died  
 1 Transferred to regular education  6 Moved, Known to be Continuing  
 2 Graduated with regular high school diploma  7 Dropped Out  
 3 Received a certificate  9 No Sp Ed, but still State DB Services  
 4 Reached Maximum Age  11 No Longer meets deaf-blind criteria

**Part B Category Code** (please indicate the primary category code under which the individual was reported on the Part B, IDEA Child Count - select only ONE. See attached GUIDELINE for additional information, if needed.):

- 1 Mental Retardation  9 Deaf-blindness  
 2 Hearing Impairment (includes deafness)  10 Multiple Disabilities  
 3 Speech or Language Impairment  11 Autism  
 4 Visual Impairment (includes blindness)  12 Traumatic Brain Injury  
 5 Emotional Disturbance  13 Developmentally Delayed - age 3-5  
 6 Orthopedic Impairment  14 Non-Categorical  
 7 Other Health Impairment  15 Not Reported under Part B of IDEA  
 8 Specific Learning Disability

**Participation in Statewide Assessments**

- 1 Regular grade-level State assessment  
 2 Regular grade-level State assessment w/accommodations  
 3 Alternate assessments aligned with grade-level achievement standards  
 4 Alternate assessments based on alternate achievement standards  
 5 Modified achievement standards  
 6 Not required at age or grade level

**Educational Setting** (indicate the ONE educational setting code from the appropriate age subcategory that best describes the individual's educational setting. Please specify "Other" if none of the provided codes apply):

**Early Intervention Setting**

Birth through 2 years of age (if the individual is in this category, please check the ONE box indicating the service(s) setting).

- |  |  |  |
|--|--|--|
| <input type="radio"/> 1 Mental Retardation                     | <input type="radio"/> 6 Orthopedic Impairment        | <input type="radio"/> 11 Autism                            |
| <input type="radio"/> 2 Hearing Impairment (includes deafness) | <input type="radio"/> 7 Other Health Impairment      | <input type="radio"/> 12 Traumatic Brain Injury            |
| <input type="radio"/> 3 Speech or Language Impairment          | <input type="radio"/> 8 Specific Learning Disability | <input type="radio"/> 13 Developmentally Delayed - age 3-5 |
| <input type="radio"/> 4 Visual Impairment (includes blindness) | <input type="radio"/> 9 Deaf-blindness               | <input type="radio"/> 14 Non-Categorical                   |
| <input type="radio"/> 5 Emotional Disturbance                  | <input type="radio"/> 10 Multiple Disabilities       | <input type="radio"/> 15 Not Reported under Part B of IDEA |

**ECSE (3-5) Settings**

- |  |  |
|--|--|
| <input type="radio"/> 1 Attending a regular EC program at least 80% of the time  | <input type="radio"/> 5 Attending a separate school      |
| <input type="radio"/> 2 Attending a regular EC program 40% to 79% of the time    | <input type="radio"/> 6 Attending a residential facility |
| <input type="radio"/> 3 Attending a regular EC program less than 40% of the time | <input type="radio"/> 7 Service provider location        |
| <input type="radio"/> 4 Attending a separate class                               | <input type="radio"/> 8 Home                             |

**School aged (6-21) Settings**

- |  |   |
|--|---|
| <input type="radio"/> 9 Inside the regular class 80% or more of the day    | <input type="radio"/> 13 Residential facility                 |
| <input type="radio"/> 10 Inside the regular class 40% to 79% of day        | <input type="radio"/> 14 Homebound/Hospital                   |
| <input type="radio"/> 11 Inside the regular class less than 40% of the day | <input type="radio"/> 15 Correctional facilities              |
| <input type="radio"/> 12 Separate School                                   | <input type="radio"/> 16 Parentally placed in private schools |

**Assistive Technology**

- |                                 |                           |                          |                               |
|---------------------------------|---------------------------|--------------------------|-------------------------------|
| Corrective Lenses               | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Unknown |
| Assistive Listening Devices     | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Unknown |
| Additional Assistive Technology | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Unknown |

**School Information**

Agency/School:			
Street Address:			
City:	State:	ZIP Code:	
Telephone Number:	Fax Number:		
Teacher's Name:			
Teacher's Email:			
School District:			

**Name of person who completed form:**

Please return this form and the appropriate Permission for Release Form (if already returned by the individual or parent/guardian), by **March 10, 2008** to:

Pennsylvania Deafblind Project/PaTTAN  
 Deafblind Census Coordinator  
 6340 Flank Drive  
 Harrisburg, PA 17112-2764

If you have any questions, please call Juli Baumgarner at (800) 446-5607, ext. 6876 or e-mail [jbaumgarner@pattan.net](mailto:jbaumgarner@pattan.net).

*Thank you for completing this form which will assist in improving student achievement.*