2019 National Deaf-Blind Child Count: Quick Reference Code Sheet

This code sheet is part of the Deaf-Blind Child Count reporting packet. Full instructions and definitions for all fields can be found in Doc I-1. Use this code sheet as a quick reference for codes for all reporting fields. Unless otherwise instructed, all missing data should be indicated by a code of 999. Enter <u>one code only</u> for all fields. Data are due May 5, 2020.

Code List

Column 1 - State

Alpha code: 2 digit uppercase letter state abbreviation.

Column 2 - Identification Code

Alpha code: 4 digit uppercase letter code created using the first two characters of the first name and the first two characters of the last name of the individual. Duplications in this field are Acceptable. For names that are hyphenated, use the first 2 characters of the beginning name of the hyphenated name. For example, John Doe-Rey would be coded as JODO.

Column 3 - Child Number

Numeric: A unique *number* (e.g., 13791) for each individual. Code numbers should remain the same for each individual across years. If your state uses state assigned student codes, it is suggested this code be used.

Column 4 - Gender

Numeric. ***Enter only one numeric code.*** Acceptable codes:

0. Male
1. Female

Column 5 - Month of Birth

Numeric. ***Enter only one numeric code.*** Acceptable format:

One or two digit month of birth.

Column 6 - Day of Birth

Numeric. ***Enter only one numeric code.*** Acceptable format:

One or two digit day of birth.

Column 7 - Year of Birth

Numeric. *Enter only one numeric code.* Acceptable format:

Four digit year of birth.

Column 8 - Etiology

Numeric. *Enter only one numeric code.* Acceptable codes:

Hereditary/Chromosomal Syndromes and Disorders

101. Aicardi syndrome

102. Alport syndrome

103. Alstrom syndrome

104. Apert syndrome (Acrocephalosyndactyly, Type 1)

105. Bardet-Biedl syndrome (Laurence Moon-Biedl)

106. Batten disease

107. CHARGE Syndrome

108. Chromosome 18, Ring 18

109. Cockayne syndrome

110. Cogan Syndrome

111. Cornelia de Lange

112. Cri du chat syndrome (Chromosome 5p- syndrome)

113. Crigler-Najjar syndrome

114. Crouzon syndrome (Craniofacial Dysotosis)

115. Dandy Walker syndrome

116. Down syndrome (Trisomy 21 syndrome)

117. Goldenhar syndrome

118. Hand-Schuller-Christian (Histiocytosis X)

119. Hallgren syndrome

120. Herpes-Zoster (or Hunt)

121. Hunter Syndrome (MPS II)

122. Hurler syndrome (MPS I-H)

123. Kearns-Sayre syndrome

124. Klippel-Feil sequence

125. Klippel-Trenaunay-Weber syndrome

126. Kniest Dysplasia

127. Leber congenital amaurosis

128. Leigh Disease

129. Marfan syndrome

130. Marshall syndrome

131. Maroteaux-Lamy syndrome (MPS VI)

132. Moebius syndrome

133. Monosomy 10p

134. Morquio syndrome (MPS IV-B)

135. NF1 - Neurofibromatosis (von Recklinghausen disease)

136. NF2 - Bilateral Acoustic Neurofibromatosis

137. Norrie disease

138. Optico-Cochleo-Dentate Degeneration

139. Pfieffer syndrome

140. Prader-Willi

141. Pierre-Robin syndrome

142. Refsum syndrome

143. Scheie syndrome (MPS I-S)

144. Smith-Lemli-Opitz (SLO) syndrome

145. Stickler syndrome

146. Sturge-Weber syndrome

147. Treacher Collins syndrome

148. Trisomy 13 (Trisomy 13-15, Patau syndrome)

149. Trisomy 18 (Edwards syndrome)

150. Turner syndrome

151. Usher I syndrome

152. Usher II syndrome

153. Usher III syndrome

154. Vogt-Koyanagi-Harada syndrome

155. Waardenburg syndrome

156. Wildervanck syndrome

157. Wolf-Hirschhorn syndrome (Trisomy 4p)

199. Other _____

Pre-Natal/Congenital Complications

201. Congenital Rubella

202. Congenital Syphilis

203. Congenital Toxoplasmosis

204. Cytomegalovirus (CMV)

205. Fetal Alcohol syndrome

206. Hydrocephaly

207. Maternal Drug Use

208. Microcephaly

209. Neonatal Herpes Simplex (HSV)

299. Other_____

Post-Natal/Non-Congenital Complications

301. Asphyxia

302. Direct Trauma to the eye and/or ear

303. Encephalitis

304. Infections

305. Meningitis

306. Severe Head Injury

307. Stroke

308. Tumors

309. Chemically Induced

399. Other _____

Related to Prematurity

401. Complications of Prematurity

Undiagnosed

501. No Determination of Etiology

Column 9- Race/Ethnicity

Numeric. *Enter only one numeric code.* Acceptable codes:

1. American Indian or Alaska Native

2. Asian

3. Black

4. Hispanic

5. White

6. Native Hawaiian /Pacific Islander

7. Two or more races

Column 10 - Documented Vision Loss

Please note: Items 5 and 8 are intentionally not used and they are unavailable as an option.

Numeric. ***Enter only one numeric code.*** Acceptable codes:

1. Low Vision (visual acuity of 20/70 to 20/200>)

2. Legally Blind (visual acuity of 20/200 or less or a field restriction of 20 degrees)

3. Light Perception Only

4. Totally Blind

5. ***Intentionally not used***

6. Diagnosed Progressive Loss, or

7. Further Testing Needed, or

8. ***Intentionally not used***

9. Documented Functional Vision Loss

Column 11 - Cortical Vision Impairment

Numeric. ***Enter only one numeric code.*** Acceptable codes:

0. No

1. Yes

2. Unknown

Column 12 - Documented Hearing Loss

Please note: Item 8 is intentionally not used or available as an option.

Numeric. ***Enter only one numeric code.*** Acceptable codes:

1. Mild   (26-40 dB loss)

2. Moderate (41-55 dB loss)

3. Moderately Severe (56-70 dB loss)

4. Severe (71-90 dB loss)

5. Profound (91+ dB loss)

6. Diagnosed Progressive Loss, or

7. Further Testing Needed, or

8. ***Intentionally not used***

9. Documented Functional Hearing Loss

Column 13 - Central Auditory Processing Disorder

Numeric. ***Enter only one numeric code.*** Acceptable codes:

0. No

1. Yes

2. Unknown

Column 14 - Auditory Neuropathy

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes

2. Unknown

Column 15 - Cochlear Implants

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes

2. Unknown

Columns 16-21 - Other Impairments or Conditions

- **Column 16 -** Orthopedic/Physical Impairments
- **Column 17 -** Cognitive Impairments
- **Column 18 -** Behavioral Disorders
- **Column 19 -** Complex Health Care Needs
- **Column 20 -** Communication/Speech/Language Impairments
- **Column 21 -** Other

Numeric. *Enter only one numeric code.* Acceptable Codes (Indicate for each field.):

0. No

1. Yes

2. Unknown

Column 22

Column 22 is intentionally not used. Previously this column was titled "Funding Category."

Column 23 - Part C Category Code

Numeric. *Enter only one numeric code.* Acceptable codes:

1. At-risk for developmental delays *(as defined by the state's Part C Lead Agency)*

2. Developmentally Delayed

888. Not Reported under Part C of IDEA

Column 24 - Part B Category Code

Numeric. *Enter only one numeric code.* Acceptable codes:

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

Column 25 - Early Intervention Setting (Birth through 2)

Numeric. *Enter only one numeric code.* Acceptable codes:

1. Home
2. Community-based settings
3. Other settings

Column 26 - Educational Setting (3-5 and 6-21)

Numeric. *Enter only one numeric code.* Acceptable codes: *(Enter only one code for 3 - 21.)*

IMPORTANT: *These codes are the "old codes" which should continue to be used for this reporting period unless you previously updated to the "new codes". If you are unsure of which codes to use, contact NCDB. Codes used for reporting will need to be submitted along with data file.*

Ages 3-5: *Early childhood special education* settings include:

1. Attending a regular early childhood program at least 80% of the time
2. Attending a regular early childhood program 40% to 79% of the time
3. Attending a regular early childhood program less than 40% of the time
4. Attending a separate class
5. Attending a separate school
6. Attending a residential facility
7. Service provider location
8. Home

Ages 6-21: *School-aged students* settings include:

9. Inside the regular class 80% or more of day
10. Inside the regular class 40% to 79% of day

11. Inside the regular class less than 40% of day

12. Separate school

13. Residential facility

14. Homebound/Hospital

15. Correctional facilities

16. Parentally placed in private schools

Column 27 - Participation in Statewide Assessments

Numeric. *Enter only one numeric code.* Acceptable codes:

1. Regular grade-level state assessment

2. Regular grade-level state assessment with accommodations

3. Alternate assessment

4. *No longer used*

5. *No longer used*

6. Not required at age or grade level

7. Parent Opt Out

Column 28 - Part C Exiting Status (Birth through 2)

Numeric. *Enter only one numeric code.* Acceptable codes:

0. In a Part C early intervention program

1. Completion of IFSP *prior to reaching maximum age* for Part C

2. Eligible for IDEA, Part B

3. Not eligible for Part B, exit with referrals to other programs

4. Not eligible for Part B, exit with no referrals

5. Part B eligibility not determined

6. Deceased

7. Moved out of state

8. Withdrawal by parent (or guardian)

9. Attempts to contact the parent and/or child were unsuccessful

Column 29 - Part B Exiting Status

Please note: Item 7 is intentionally not used or available as an option.

Numeric. *Enter only one numeric code.* Acceptable codes:

0. In ECSE or school-aged special education program

1. Transferred to regular education

2. Graduated with regular high school diploma

3. Received a certificate

4. Reached maximum age

5. Died

6. Moved, known to be continuing

7. *Intentionally not used*

8. Dropped out

Column 30 – Deaf-Blind Project Exiting Status

Numeric. *Enter only one numeric code.* Acceptable codes:

0. Eligible to receive services from the deaf-blind project

1. No longer eligible to receive services from the deaf-blind project

Column 31 - Living Setting

Numeric. *Enter only one numeric code.* Acceptable codes:

1. Home: Parents
2. Home: Extended family
3. Home: Foster parents
4. State residential facility
5. Private residential facility

6. Group home (less than 6 residents)
7. Group home (6 or more residents)
8. Apartment (with non-family person(s))
9. Pediatric nursing home
555. Other

Column 32 - Corrective Lenses

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes

2. Unknown

Column 33 - Assistive Listening Devices

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes

2. Unknown

Column 34 - Additional Assistive Technology

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes

2. Unknown

Column 35 – Intervener Services

Numeric. *Enter only one numeric code.* Acceptable codes:

0. No

1. Yes (from an individual with the title and function of an intervener **OR** from an individual with the function of an intervener working under a different title)

2. Unknown

Quick Codes in Tables

Column 4 - Gender	
0. Male	1. Female

Column 8 - Primary Identified Etiology	
Hereditary/Chromosomal Syndromes and Disorders	
101 Aicardi syndrome	130 Marshall syndrome
102 Alport syndrome	131 Maroteaux-Lamy syndrome (MPS VI)
103 Alstrom syndrome	132 Moebius syndrome
104 Apert syndrome (Acrocephalosyndactyly, Type 1)	133 Monosomy 10p
105 Bardet-Biedl syndrome (Laurence Moon-Biedl)	134 Morquio syndrome (MPS IV-B)
106 Batten disease	135 NF1 - Neurofibromatosis (von Recklinghausen disease)
107 CHARGE Syndrome	136 NF2 - Bilateral Acoustic Neurofibromatosis
108 Chromosome 18, Ring 18	137 Norrie disease
109 Cockayne syndrome	138 Optico-Cochleo-Dentate Degeneration
110 Cogan Syndrome	139 Pfieffer syndrome
111 Cornelia de Lange	140 Prader-Willi
112 Cri du chat syndrome (Chromosome 5p- syndrome)	141 Pierre-Robin syndrome
113 Crigler-Najjar syndrome	142 Refsum syndrome
114 Crouzon syndrome (Craniofacial Dysotosis)	143 Scheie syndrome (MPS I-S)
115 Dandy Walker syndrome	144 Smith-Lemli-Opitz (SLO) syndrome
116 Down syndrome (Trisomy 21 syndrome)	145 Stickler syndrome
117 Goldenhar syndrome	146 Sturge-Weber syndrome
118 Hand-Schuller-Christian (Histiocytosis X)	147 Treacher Collins syndrome
119 Hallgren syndrome	148 Trisomy 13 (Trisomy 13-15, Patau syndrome)
120 Herpes-Zoster (or Hunt)	149 Trisomy 18 (Edwards syndrome)
121 Hunter Syndrome (MPS II)	150 Turner syndrome
122 Hurler syndrome (MPS I-H)	151 Usher I syndrome
123 Kearns-Sayre syndrome	152 Usher II syndrome
124 Klippel-Feil sequence	153 Usher III syndrome
125 Klippel-Trenaunay-Weber syndrome	154 Vogt-Koyanagi-Harada syndrome
126 Kniest Dysplasia	

127 Leber congenital amaurosis	155 Waardenburg syndrome
128 Leigh Disease	156 Wildervanck syndrome
129 Marfan syndrome	157 Wolf-Hirschhorn syndrome (Trisomy 4p)
	199 Other _____
Pre-Natal/Congenital Complications	**Post-Natal/Non-Congenital Complications**
201 Congenital Rubella	301 Asphyxia
202 Congenital Syphilis	302 Direct Trauma to the eye and/or ear
203 Congenital Toxoplasmosis	303 Encephalitis
204 Cytomegalovirus (CMV)	304 Infections
205 Fetal Alcohol syndrome	305 Meningitis
206 Hydrocephaly	306 Severe Head Injury
207 Maternal Drug Use	307 Stroke
208 Microcephaly	308 Tumors
209 Neonatal Herpes Simplex (HSV)	309 Chemically Induced
299 Other_____	399 Other _____
Related to Prematurity	**Undiagnosed**
401 Complications of Prematurity	501 No Determination of Etiology

Column 9 - Race/Ethnicity

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Hispanic/Latino

5. White
6. Native Hawaiian/Pacific Islander
7. Two or more races

Column 10 – Documented Vision Loss (Items 5 and 8 are intentionally not used and they are unavailable as an option)

1. Low Vision
2. Legally Blind
3. Light Perception Only
4. Totally Blind

6. Diagnosed Progressive Loss
7. Further Testing Needed (1 year only)
9. Documented Functional Vision Loss

Column 11 -Cortical Vision Impairment		
0. No	1. Yes	2. Unknown

Column 12 -Documented Hearing Loss (Item 8 is intentionally not used and it is unavailable as an option)

1. Mild
2. Moderate
3. Moderately Severe
4. Severe

5. Profound
6. Diagnosed Progressive Loss
7. Further Testing Needed (1 year only)
9. Documented Functional Hearing Loss

Column 13 - Central Auditory Processing Disorder		
0. No	1. Yes	2. Unknown

Column 14 - Auditory Neuropathy		
0. No	1. Yes	2. Unknown

Column 15 - Cochlear Implant		
0. No	1. Yes	2. Unknown

Column 16 - Other Impairments or Conditions Orthopedic/Physical Impairments		
0. No	1.Yes	2. Unknown

Column 17- Other Impairments or Conditions-Cognitive	
0. No	1. Yes

Column 18- Other Impairments or Conditions-Behavioral	
0. No	1. Yes

Column 19- Other Impairments or Conditions-Complex Health Care Needs	
0. No	1. Yes

Column 20- Other Impairments or Conditions-Communication, Speech/Language	
0. No	1. Yes

Column 21- Other Impairments or Conditions	
0. No	1. Yes

Column 22 is intentionally not used. (Previously this column was titled "Funding Category".)

Column 23 - Part C Category Code

1. At-risk for developmental delays (as defined by the state's Part C Lead Agency) 2. Developmentally Delayed	Also included for Child Count reporting purposes are: 888. Not Reported Under Part C

Column 24 - Part B Category Code

1. Intellectual Disability	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 through 9
6. Orthopedic Impairment	Also included for Child Count reporting purposes are:
7. Other Health Impairment	14. Non-Categorical
8. Specific Learning Disability	888. Not Reported under Part B of IDEA

Column 25 - Early Intervention Setting (Birth through 2)

1. Home	2. Community-based settings	3. Other settings

Column 26 - Educational Setting (3-21)

Ages 3-5: ECSE Settings	Ages 6-21: School aged settings
1. Attending a regular early childhood program at least 80% of the time 2. Attending a regular early childhood program 40% to 79% of the time 3. Attending a regular early childhood program less than 40 % of the time 4. Attending a separate class 5. Attending a separate school 6. Attending a residential facility 7. Service provider location 8. Home	9. Inside the regular class 80% or more of day 10. Inside the regular class 40% to 79% of day 11. Inside the regular class less than 40% of day 12. Separate school 13. Residential facility 14. Homebound/Hospital 15. Correctional facilities 16. Parentally placed in private schools

Column 27 – Participation in Statewide Assessments

1. Regular grade-level state assessment	*4. **Not Used***
2. Regular grade-level state assessment with accommodations	*5. **Not Used***
3. Alternate assessments	6. Not required current age/grade level
	7. Parent Opt Out

Column 28 - Part C Exiting Status (Birth through 2)

0. In a Part C early intervention program	5. Part B eligibility not determined
1. Completion of IFSP prior to reaching maximum age for Part C	6. Deceased
2. Eligible for IDEA, Part B	7. Moved out of state
3. Not eligible for Part B, exit with referrals to other programs	8. Withdrawal by parent (or guardian)
4. Not eligible for Part B, exit with no referrals	9. Attempts to contact the parent and/or child were unsuccessful

Column 29 - Part B Exiting

0. In ECSE or school-aged special education program	5. Died
1. Transferred to regular education	6. Moved, known to be continuing
2. Graduated with regular diploma	7. **(intentionally not used)**
3. Received a certificate	8. Dropped out
4. Reached maximum age	

Column 30 – Deaf-Blind Project Exiting Status

0. Eligible to receive services from the deaf-blind project	1. No longer eligible to receive services from the state deaf-blind project

Column 31 - Living Setting

1. Home: With parents	6. Group home (less than 6 residents)
2. Home: Extended family	7. Group home (6 or more residents)
3. Home: Foster parents	8. Apartment (with non-family person(s))
4. State residential facility	9. Pediatric nursing home
5. Private residential facility	555. Other (Specify) _____

Column 32 - Corrective Lenses		
0. No	1. Yes	2. Unknown

Column 33 - Assistive Listening Devices		
0. No	1. Yes	2. Unknown

Column 34 - Additional Assistive Technology		
0. No	1. Yes	2. Unknown

Column 35 – Intervener Services		
0. No	1. Yes	2. Unknown

<u>Submission Instructions</u>

Data are due by May 5, 2020 and should be submitted via our secure portal in a format that can be opened in Microsoft Excel (.csv, .xls, or .xlsx). When ready to submit**,** visit the **Annual Resources for Reporting the Child Count** web page for submission instructions. Please call or email Robbin Bull, robbin.bull@hknc.org PH: 503-831-4649, for any additional information or clarifications related to the DB Child Count reporting process.