# 2020 National Deaf-Blind Child Count Revisions

The purpose of this document is to provide an overview of revisions to the National Deaf-Blind Child Count (DBCC) reporting materials.

## Rationale

The National Center on Deaf-Blindness and State Deaf-Blind Projects are committed to using high-quality practices and products to improve outcomes for children who are deaf-blind. Collecting and analyzing demographic information of children who are deaf-blind is instrumental in developing project priorities based on data documenting their needs. From time to time, it is necessary to re-evaluate the child count to make sure it is providing the information needed to effectively serve children and youth who are deaf-blind. The last time a needs assessment of this magnitude was conducted was in 2006.

## Process

In February 2020, NCDB sought input from state deaf-blind project personnel regarding the overall usefulness, barriers, gaps, process, and formatting of the DBCC collection and reporting materials through a needs assessment survey ([see results](https://docs.google.com/document/d/1tX5BSbC_M4yWVIcbbsy2sTmMEAw8OzJhDTsXtyG3o3A/edit?usp=sharing)). Needs assessment feedback was reviewed and prioritized by a work group consisting of NCDB staff and state deaf-blind project representatives. Proposed revisions incorporated the work group’s recommended revisions, OSEP requirements, and NCDB national reporting needs. A two-week comment period was open for final feedback from state deaf-blind projects. Revisions will be implemented\* with the December 1, 2020 National Deaf-Blind Child Count to be submitted May 2021.

*\*A “phase-in implementation” will be allowed. SDBPs can 1) choose to fully implement the designated changes with the December 1, 2020 DBCC, 2) implement some of the changes for the 2020 DBCC, or 3) choose to wait and fully implement all changes with the December 1, 2021 DBCC. All changes must be implemented for the December 1, 2021 DBCC.*

## Acknowledgements

Many thanks to the Deaf-Blind Child Count Work Group members who provided thoughtful consideration to feedback from the field. Many hours went into reviewing materials and forming recommendations.

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## Revisions

Each DBCC item is listed in the table below with the status of the revision, issue(s) addressed, and an explanation. An overall change to the DBCC includes the removal of column references to allow for flexibility to re-organize the collection of information, if needed. Items in the table below are in the new order, but state deaf-blind projects may order their data and collection materials in a way that is most useful for project management. To ease the burden on state projects, data will be permitted to be submitted to the NCDB in the column order that best suits each project. In addition, main sections have been added as an organizational tool, but state projects are not required to use the section titles or groupings. A list of the new order of items is at the end of this document.

| **Item Name** | **Status** | **Issue** | **Revision Explanation** |
| --- | --- | --- | --- |
| ***SECTION: Internal Reporting Information*** | *New* | *Confusion about what items should be collected and what items are for internal reporting purposes.**Information is not structured in a logical order.* | *A new section was added for items that are administrative in nature. These are items that are generally dealt with internally by a project and used for reporting purposes, but not collected on individual referral or update forms.* |
| State | No Change | No Issues | Maintain 2-character USPS state abbreviation. |
| Identification Code | Updated | Does not uniquely identify records. Seems duplicative with the purpose of Child Number. | **Optional.** Historically this item was designed to create a consistent identifying code for children/youth.Although not used to uniquely identify children when combined with Child Number, it can be useful for tracking children/youth across years. Some state projects heavily rely on it to manage their child count and use in communication with NCDB. This item is now optional, **as long as a state project uses truly unique codes for Child Number and maintains a consistent code for each child the entire time they are on the child count.** |
| Child Number | Updated | Some states feel this is duplicative to Identification Code. Some states feel there needs to be more guidance on creating codes. | **Added Detail:** Child Number should be a unique identifier created by the state deaf-blind project. It can be any combination of numbers and characters a project chooses. Similar to a Social Security Number, the number assigned should only be used for this one child and remain the same for the child the entire time they are on the child count. This allows the child to be tracked across different reporting years. State projects may wish to use a state assigned number if their states have them, to allow for data sharing and communication between agencies, however this is just a suggestion. If the Child Number needs to be changed for some reason, comments should be provided in the new Data Notes field. |
| Newly Identified  | NEW | State projects must report this information on the APR and NCDB runs national reports on this information. There is no easy and reliable way to extract this information from the child count. | **Field name: NewID. Internal use only. This data is not collected on child count forms.**This item will be helpful for calculating the Newly Identified common measure. Some projects may already have this data in their databases as a “new referral date” or “eligibility date.” Using a date field will help extract the data each year. Eligibility for state deaf-blind project services vary among states, therefore each state will determine their own criteria for “Newly Identified.”  |
| Deaf-Blind Project Status | Moved and Updated | There is a lot of confusion about this field. Some feel it is duplicative of IDEA Part C or B Exiting. Eligibility criteria vary by state, so this seems redundant or unnecessary for some projects. | **Internal use only. This data is not usually collected on child count forms.**The word “exiting” has been removed from the label to reduce confusion. This is being retained because it is important for processing national data. Data in this field may influence whether or not a child in included in the December 1 Snapshot number reported for a state.This item should be completed by state deaf-blind projects for all children/youth to indicate the last reporting year for students who, sometime during the reporting year, became ineligible for deaf-blind project services. Ineligibility may be due to such things as moving out of state, aging out, death, no longer meeting deaf-blind project eligibility criteria, unable to locate. Some projects inactivate student records immediately once they become ineligible and do not report data for the last reporting year. Projects should adjust their systems to allow for reporting data for the year a child/youth became ineligible for project services. In some states, eligibility and IDEA Part C or B Exiting align, while in others they do not. Therefore, in some states a student may have exited Part C or B, but still be eligible for deaf-blind project services. |
| Data Notes | NEW |  | Use to provide more detail as needed on unusual or noteworthy circumstances or changes that may cause data to appear out of range. This information may or may not be published. The primary function of this field is clarification. This is an internal reporting field. |
| ***SECTION: Demographic Information*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information that is demographic in nature.* |
| Gender | Updated | There is a growing desire to allow for more options for gender. | **An additional choice was added as an option.** Due to the variety of terminology options, a general option of Other, in addition to Male and Female, was added. A project may collect sub-category options for Other using terminology they deem appropriate for their state. Use of Other is optional but, if used, category choices in addition to Male and Female should be aggregated into Other for national reporting.  |
| *Date of Birth: two reporting format options* | Optional Format | Some feel date of birth is unnecessary. One date field rather than three separate fields for collecting this data would be more efficient.  | Date of Birth is important for creating national and state reports based on age. It helps us understand needs at different ages to guide TA efforts. Date of Birth can now be reported in one of two ways. **Data does not need to be reported both ways.**DOB is a new date field option that makes it possible to enter the full birthdate into one field. Many projects already have birthdate information in their database systems in this fashion. There is no need to separate it into three separate M/D/Y fields for reporting since NCDB converts this data into a date field for calculations. If data is not already in a date field, a simple script can often be run to convert data from a three field format into one date field.Birth Month/Birth Day/Birth Year fields are kept as an option for projects who do not choose to convert at this time. NCDB can easily continue to process data from the three fields.Projects can use a mix of these two methods if they want to transition from three fields to the one DOB field over time. |
| DOB | New | See *Date of Birth: two reporting format options* above for more details. | **Optional.** This is NCDB’s preferred method for receiving date of birth data. In some cultures, it is difficult to get exact birth day information. If day is unknown, “15” may be used. See *Date of Birth: two reporting format options* above for more details. |
| Birth Month | Updated | See *Date of Birth: two reporting format options* above for more details. | Must be used if *DOB* is not used. Optional if *DOB* is used. All children must have date of birth information. |
| Birth Day | Updated | See *Date of Birth: two reporting format options* above for more details. | Must be used if *DOB* is not used. Optional if *DOB* is used. All children must have date of birth information. If unknown, default to “15” and note in data notes. |
| Birth Year | Updated | See *Date of Birth: two reporting format options* above for more details. | Must be used if *DOB* is not used. Optional if *DOB* is used. All children must have date of birth information. |
| Ethnicity | New | Race and ethnicity were not aligned with federal reporting guidelines for collecting data. | Although we collapse ethnicity information into the 7 race/ethnicity reporting categories to align with the IDEA Part B reports, federal guidelines for collecting race and ethnicity data mandate that the information is collected in a two-part question that gives individuals an opportunity to first indicate if their ethnicity is Hispanic/Latino or not, regardless of race. A second question provides race options. Both Ethnicity and Race must be completed. A new support document, *Guidelines for Reporting Ethnicity and Race* has been created to provide further guidance. |
| Race | Updated  | Race and ethnicity were not aligned with federal reporting guidelines for collecting data. | Although we collapse ethnicity information into the 7 race/ethnicity reporting categories to align with the IDEA Part B reports, federal guidelines for collecting race and ethnicity data mandate that the information is collected in a two-part question that gives individuals an opportunity to first indicate if their ethnicity is Hispanic/Latino or not, regardless of race. A second question provides race options. Both Ethnicity and Race must be completed. A new support document, *Guidelines for Reporting Ethnicity and Race* has been created to provide further guidance. |
| Living | Moved | Out of logical order. Some items rarely used. Language was outdated. | The two group home options and the apartment option were collapsed into a new option entitled “Community Residence (Includes group home/supported apartment)” |
| Primary Language in the Home | NEW | Understanding the diversity of the families we serve is useful. This would help gain a picture of needed languages for cultural awareness, materials, and trainings. | **Optional.** At this time, the work group did not determine it was necessary to require projects to collect primary language on a national level, but we encourage the collection and reporting of this category for projects that feel it is useful. NCDB will aggregate data received by projects who report this information and monitor this category for future inclusion as a required item. |
| Etiology | Retain | Although useful information, some projects struggle with information collected being incorrect or unknown.“Other” seems to be useless. | Information on the causes of deaf-blindness is important for increasing awareness, identifying trends, and sharing with health care providers and others to improve identification. Projects have the flexibility to add additional supporting language to state collection materials to improve the accuracy of this information within their states.NCDB will provide an online [list of etiologies](https://www.nationaldb.org/db-child-count-etiology-code-list/) that state projects can link to in their collection materials, if they so choose.Although “other” data is not published, we do maintain a database of “other” etiologies. We have used this in the past to connect projects that have children/youth with rare etiologies. We encourage projects to continue collecting and reporting this information. |
| ***SECTION: Vision Information*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information related to vision for a more logical flow.* |
| Documented Vision Loss | Updated | Old, unused codes were still in code list.Some states expressed an interested in collecting more detailed information. | Unused codes were removed from code list.It was not determined that additional information for this category is required on a national basis, but projects have the flexibility to collect additional information for their own needs. |
| Cortical Vision Impairment/Cerebral Visual Impairment (CVI) | Updated | Terminology needs to be updated to reflect current language. | The label was expanded to reflect current terminology used in the field. Information from this category provides data to help paint a picture of the complexities of the population and highlights areas for awareness, training, and education. A basic definition has been added. |
| ***SECTION: Hearing Information*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information related to hearing for a more logical flow.* |
| Documented Hearing Loss  | Updated | Old, unused codes were still in code list.Some states expressed an interested in more detailed information collected. | Unused codes were removed from code list.It was not determined that additional information for this category is required on a national basis, but projects have the flexibility to collect additional information for their own needs. |
| Central Auditory Processing Disorder (CAPD) | Updated | Additional information is needed to understand why this is not included with Documented Hearing Loss. | Central Auditory Processing Disorder is a distinct type of hearing impairment. Information from this category provides data to help paint a picture of the complexities of the population and highlights areas for awareness, training, and education. A basic definition has been added. Learn more about [CAPD](https://www.asha.org/Practice-Portal/Clinical-Topics/Central-Auditory-Processing-Disorder/). |
| Auditory Neuropathy | Updated | Additional information is needed to understand why this is not included with Documented Hearing Loss. | Auditory Neuropathy is a distinct type of hearing impairment. Information from this category provides data to help paint a picture of the complexities of the population and highlights areas for awareness, training, and education. A basic definition has been added. Learn more about [Auditory Neuropathy](https://www.nidcd.nih.gov/health/auditory-neuropathy). |
| Cochlear Implants | No Changes | Some projects indicated a desire to collect more specific information. | It was not determined that additional information for this category is required on a national basis, but projects have the flexibility to collect additional information for their own needs. |
| Assistive Listening Devices | No Changes | Unclear purpose of item. Terminology may be out of date or insufficient. | It was not determined that additional information for this category is required on a national basis, but projects have the flexibility to collect additional information for their own needs. Information from this category provides data to help paint a picture of the complexities of the population and highlights areas for awareness, training, and education. |
| ***SECTION: Other Impairments*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information related to other impairments for a more logical flow.* |
| Other Impairments: Orthopedic/Physical Impairment | Updated | No definitions so data is unreliable.Labels don’t align with Part B disabilities. | The label was updated to incorporate terminology from the Part B Disability category while maintaining the old terminology. The definition for “Part B disability: Orthopedic Impairment” was added. |
| Other Impairments: Intellectual/Cognitive Disabilities | Updated | No definitions so data is unreliable.Labels don’t align with Part B disabilities. | The label was updated to incorporate terminology from the Part B Disability category while maintaining old terminology. The definition for “Part B Disability: Intellectual Disabilities” was added. |
| Other Impairments: Emotional/Behavioral Disorders | Updated | No definitions so data is unreliable.Labels don’t align with Part B disabilities. | The label was updated to incorporate terminology from the Part B Disability category while maintaining old terminology. The definition for “Part B Disability: Emotional Disorders” was added. |
| Other Health Impaired/ Complex Health Care Needs | Updated | No definitions so data is unreliable.Labels don’t align with Part B disabilities. | The label was updated to incorporate terminology from the Part B Disability category while maintaining old terminology. The definition for “Part B Disability: Other Health Impaired” was added.An additional definition to describe complex health care needs was also included.  |
| Other Impairments: Communication/Speech/Language Impairments | Updated | No definitions so data is unreliable.Labels don’t align with Part B disabilities. | The label was updated to incorporate terminology from the Part B Disability category while maintaining old terminology. The definition for “Part B Disability: Speech or Language” was added. |
| Other Impairments: Other | Updated | No definitions so data is unreliable. | This item provides an opportunity to collect information that may otherwise be missed and is useful for TA or training. Projects have the flexibility to add language to their state collection materials to provide additional guidance as needed. |
| ***SECTION: Educational Supports*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information related to educational supports for a more logical flow.* |
| Additional Assistive Technology | Moved and Updated | No definition so data is unreliable. | Updated definition. |
| Intervener | Moved and Updated | Out of order. | N/A option was added for children who are too young for an intervener. |
| ***SECTION:******Services*** | *New* | *Information is not structured in a logical order.* | *This section was created to group information related to services for a more logical flow.* |
| Funding (Blank) | Removed | Due to column numbers this is used as a placeholder and still shows up on the spreadsheet template and data files even though no longer used. | This is described as “removed” because it was discontinued years ago. A similar field is being added called IDEA Services. Some projects who still have the Funding field in their databases may be able to transition this field into the new IDEA Services field, but the data will need to be verified (see below). |
| IDEA Services | NEW | Part C is generally ages Birth - 2 and Part B is 3 - 21, however there are exceptions. Some children do not receive IDEA services and it is difficult to clearly indicate that in the current format.  | This field has been added to clearly identify the services a child is receiving. This is necessary for data validation procedures. Category options stay aligned with Funding options, where possible, for those transitioning from the old field to this one.  |
| Part C Category Code | Updated | Unclear how to handle data reporting when child is over age 2. Value of information is unclear. | A Not Applicable (N/A) code has been added to the options list. Children who age out of Part C and have a Part B Disability Code should also have the N/A code for this field.This information helps us align our information with the IDEA 618 Part C data and strategize with other TA Centers and organizations on awareness and identification. |
| Part C EI Setting | Updated and Moved | Out of logical order. Unclear how to handle data reporting when child is over age 2. Value of information is unclear. | This field was moved and is now grouped with other questions related to Part C/Birth - Age 2. A Not Applicable (N/A) code has been added to the options list. Children who age out of Part C and have a Part B Disability Code should also have the N/A code for this field.This information helps us align our information with the IDEA 618 Part C data and strategize with other TA Centers and organizations on awareness and identification. |
| Part C Exiting Status | Updated and Moved | Out of logical order. Unclear how to handle data reporting when child is over age 2. Value of information is unclear. | This field was moved to be grouped with other questions related to Part C. A Not Applicable (N/A) code has been added to the options list. Children who age out of Part C and have a Part B Disability Code should also have the N/A code for this field.This information helps us align our information with the IDEA 618 Part C data and strategize with other TA Centers and organizations on awareness and identification. |
| Part B Disability Code | Updated and Moved | Out of logical order. Reference to data coming from State Department of Education Part B, IDEA Child Count was misleading. Unclear how to handle data reporting when child is under age 3. Label was confusing. | Moved to be grouped with other questions related to Part B. Although disability codes are used for Part B Child Count reporting, it is difficult to say accurately that this is the information reported on the Part B Child Count. A broader description has been given. A Not Applicable (N/A) code has been added to the options list. Children who are in Part C and have a Part C Disability Code should also have the N/A code for this field. |
| Part B Education Environments | Updated and Moved | Out of logical order. Major code mix-up in 2018 has caused data to become unreliable.Home schooling causes a lot of confusion for coding for projects.COVID-19’s impact on the educational system will increase the challenges of determining the best educational environment to describe student’s situation.Unclear how to handle data reporting when child is under age 3. Label was confusing. | Moved to be grouped with other questions related to Part B. Label has been changed to align with IDEA 618 Part B Category Label.Service Provider Location in the ECSE group has been removed.Language for Early Childhood Education Environments have been updated to align with IDEA 618 language. **All code numbers for ECSE and School-Age Education Environments have been changed.** Requiring all projects to update their codes will give NCDB and state projects an opportunity to review the data and reset the coding. For some projects, a simple script can be used to convert codes for all records to the new codes. NCDB will provide further guidance on this process.Due to frequent questions related to home schooling and anticipated shifts in education environments due to COVID-19, additional home/home school options have been added to both the ECSE and School-Age lists. A Not Applicable (N/A) code has been added to the options list. Children who are in Part C and have a Part C EI Setting Code should also have the N/A code for this field. |
| Participation in Statewide Assessments | Updated | Old, unused options were still in options list as placeholders, which caused confusion. | Unused options were removed from list. A temporary code has been added for reporting when a state did not do statewide testing due to COVID-19.  |
| Part B Exiting Status  | Updated | Alignment with IDEA Part B only requires collecting this information for ages 14-21. | **Optional for ages 3-13**. For national reporting, we will only aggregate data for ages 14-21 for this category. States that find the options (moved, transferred to regular education, died) applicable to the 3-13 year olds informative may choose to continue to collect this information for those ages as well. This data can still be included in your data file sent to NCDB, but will not be used for the national report for this category.Graduated with an alternate diploma has been added as an option for those states where this is used.Additional detail has been added to labels and federal descriptors were updated to increase clarity.  |

## Full list of new item order by section:

SECTION: Internal Reporting Information

* State
* Identification Code
* Child Number
* Newly Identified
* Deaf-Blind Project Status
* Data Notes

SECTION: Demographic Information

* Gender
* DOB
* Ethnicity
* Race
* Living
* Primary Language in the Home
* Etiology

SECTION: Vision Information

* Documented Vision Loss
* Cortical Vision Impairment (CVI)

SECTION: Hearing Information

* Documented Hearing Loss
* Central Auditory Processing Disorder (CAPD)
* Auditory Neuropathy
* Cochlear Implants
* Assistive Listening Devices

SECTION: Other Impairments

* Orthopedic/Physical Impairment
* Intellectual/Cognitive Disabilities
* Emotional/Behavioral Disorders
* Other Health Impaired/Complex Health Care Needs
* Communication/Speech/Language Impairments
* Other

SECTION: Educational Supports

* Additional Assistive Technology
* Intervener

SECTION: Services

* IDEA Services
* Part C Disability Category Code
* Early Intervention Setting
* Part C Exiting Status
* Part B Disability Code
* Education Environment
* Participation in Statewide Assessments
* Part B Exiting Status