

The American Printing House for the Blind
In conjunction with
Nebraska Center for the Education of Children Who Are Blind or Visually Impaired
P.O Box 129
Nebraska City, NE 68410
1-800-826-4355

The Babies Count Project
The National Registry for Children with Visual Impairments,
Birth to Three

<p style="text-align: center;">MANUAL Instructions for Completing Data Collection Form</p>

PLEASE read the entire manual before completing the Survey Form.
PLEASE complete the Survey Form in ink (write legibly & fairly large).

SUBMITTING FORMS

- Initial Submittal Date: Indicate if this is a new registration.

Updates: You are permitted **THREE** updates. The 3rd update is used to indicate the child has EXITED the program.

If you send your surveys to APH, you determine the update dates and the same number of updates are available.

IMPORTANT: It is important to share with parents/guardians that they do not have to provide information that makes them feel uncomfortable, or seems too personal to share. This should be explained prior to completing the Survey Form.

SUGGESTION: After completing the Survey Form, you may want to make a copy for your file.

SURVEY FORM SUBMITTAL INFORMATION

VERY IMPORTANT: Please provide **all** information requested in the box on front of Survey Form under Survey Form Submittal Information. Individuals completing the survey form should provide the requested information. Survey Form should not be given to parent/guardian to complete.

CHILD INFORMATION

Program Identification: TO BE COMPLETED BY NCECBVI STAFF

1. Gender: Indicate child's gender.
3. Ethnicity of child: Check box that represents the child's ethnic origin. If you select "other", please indicate ethnicity in writing. Please mark other if child is of more than one ethnicity (identify ethnicities).
4. Location of primary residence: Indicate the state and the zip code where the child lives. Indicate entire nine-digit zip code, if known.
5. Date of Birth: Indicate date child was born by month/day/year (write date as m/d/y NOT m-d-y)
6. Gestational Age at Birth: Determine child's gestational age at birth from medical records or parent interview. Gestational age is usually reported in weeks from conception, and this is the preferred entry here. "Full Term" or gestational age in months may also be reported. Seek this entry first from the medical record, if available. If not available, ask parents.
7. Gestational Information Obtained From: Please indicate the source of information about child's gestational age.
8. Birth Weight: Indicate child's weight at birth in grams (preferred) or pounds and ounces (when listed as grams, you can click on pound and it will automatically convert to pounds and ounces).
9. Multiple Birth: Indicate if this child was the product of a multiple birth/pregnancy/gestation.
10. Date of visual diagnosis (preferred) or age (in nearest whole month) at time of diagnosis: Indicate the date the visual diagnoses was made. If this date is not available, give the age (months) of the child). Write date as m/d/y NOT m-d-y.
11. Referral Date: Indicate the month/day/year that family or referral source

made first contact with this program. Write date as m/d/y NOT m-d-y.

12. Entry Date: Indicate the month/day/year that services were initiated by the agency completing this form for this child. Write date as m/d/y NOT m-d-y.

FAMILY INFORMATION

Information about parents/guardians: In a two parent household, the information should be filled out for both adults.

13. Biological mother's date of birth (preferred): Indicate the biological mother's date of birth, if known.
14. Biological father's date of birth (preferred): Indicate the biological father's date of birth, if known.
15. Child currently resides primarily with: Indicate all persons with whom the child currently lives. For mother and father indicate the relation: biological, foster, adoptive, or step. For grandparents, indicate if the child lives with maternal or paternal. "Other adult" would include related (aunts, uncles), or unrelated persons that may live in the home. If there are siblings, indicate number.
16. Primary language spoken in the home: Indicate the language used most often in the home.
17. Level of education completed: Indicate highest level of education completed by both parents or guardians. If you indicate grade completed, you must indicate the highest grade completed.

MEDICAL INFORMATION

Information in questions #18 -#21 **must** be obtained from medical reports. Visual behaviors and other visual conditions not considered "diagnoses" may be included in questions #22 and #23. Stars appear where the visual condition cannot be considered a primary or additional diagnosis. For example, albinism is never considered an additional diagnosis, so no box is given. For each eye, check **only one** condition under "primary" and all that apply under "additional".

18. Primary visual diagnosis (left eye): Indicate the primary visual diagnosis for this child in the left eye, as determined by a medical report. Be as precise as possible and check **only** one.
19. Additional diagnosis (left eye): Indicate additional visual diagnosis in the

child's left eye, as determined by a medical report. Check **all** that apply.

20. Primary visual diagnosis (right eye): Indicate the primary visual diagnosis for this child in the right eye, as determined by a medical report. Be as precise as possible and check **only** one.
21. Additional diagnosis (right eye): Indicate additional visual diagnosis in the child's right eye, as determined by a medical report. Check **all** that apply.
22. Visual Behaviors (indicate **all** visual behaviors present):
- * Eccentric viewing: Child appears not to look at objects directly, or looks at objects while turning head to side.
 - * Eye poking: Child places fingers or objects directly into eye.
 - * Eye pressing: Child applies pressure to the eye and/or socket.
 - * Gaze aversion: Child intentionally looks away from lights, persons, and/or objects.
 - * Head shaking: Child displays excessive head movement.
 - * Inconsistent visual performance: Child responds inconsistently to visual stimuli.
 - * Light gazing: Child consistently fixates on light for an extended period of time.
 - * Photophobia: Child displays discomfort from extreme sensitivity to light.
 - * Tearing: Child's eyes tear excessively.
 - * Responds to objects only if held close: Child consistently holds objects within four inches of eyes.
 - * None: Please indicate **none** if no unusual behaviors are observed.
 - * Other: Additional behaviors that you feel indicate the presence or absence of vision. Please fill in the blank.
23. Other visual conditions: Indicate other visual conditions from the medical report that were not listed as "primary" or "additional" diagnoses. Indicate **none** if no other visual conditions are present. Please fill in the blank if your response is **other**. PLEASE see glossary for additional information.
24. Does the child use: Does the child have corrective lenses or prostheses? If so, indicate the type.
25. Based on medical records, is the child legally blind? For legal blindness use the definition: Best corrected visual acuity of 20/200 or less, or visual field reduced to 20 degrees or less in the better seeing eye. Please use information from child's **medical** records.

Tested Visual Acuity: For items #26 - #28 use reported acuity numbers or the following APH codes:

- * HM Hand Movements: Should be used only when an eye specialist determines it is not possible to obtain an acuity using the Snellen Chart.
- * CF Counts Fingers: Should be used only when an eye specialist

determines it is not possible to obtain an acuity using the Snellen Chart.

- * OP Object Perception
- * LP Light Perception
- * TB Totally Blind

26. Right Eye (O. D.): Indicate the reported visual acuity of the right eye with and without correction. This information should be obtained from medical records, when possible. Please check **unknown** when not available.
27. Left Eye (O. S.): Indicate the reported visual acuity in the left eye with and without best correction. This information should be obtained from medical records, when possible. Please check **unknown** when not available.
28. Both Eyes (O. U.): Indicate the reported visual acuity in both eyes with or without best correction. This information should be obtained from medical records, when possible. Please check **unknown** when not available.
29. How was visual acuity determined? Indicate test used to determine visual acuity.

Observation Of Functional Vision: For items #30 - #32, please indicate behaviors that have been observed; parent report is acceptable. Check all that apply.

30. Awareness of: Child responds to faces, objects, and/or lights by smiling, a change in breathing, or turning toward or away from light.
31. Attention/Fixation on: Child establishes and maintains gaze on faces, objects, and/or lights.
32. Following/Tracking of: Child visually follows moving faces, objects, and/or lights.
33. Etiology of Visual Impairment: Indicate the exact cause of the visual impairment, if known, based on medical documentation. If uncertain, please **check** unknown. If other, please **write in** specific cause.
34. Additional Medical and Health Conditions: Indicate if there are any additional medical or health conditions present. Obtain information from child's medical records and check all that apply. If **none**, please check **none**.
35. Hearing Test Results: If you indicate "within normal limits" or "not within normal limits," you **must** indicate "aided" or "unaided" or you cannot continue to the next page when using the on-line entry.

EARLY INTERVENTION SERVICE INFORMATION

36. Family Referred for Services by: Indicate who initially referred the family to the agency. Check **one** box and identify the referral source. Please do not give names. For example:
- * Medical Provider: Ophthalmologist, optometrist, neurologist, pediatrician
 - * Public Agency: Interagency Council, Part C
 - * Early Intervention Program: Easter Seals, United Cerebral Palsy
 - * Family/friend/mother/father
 - * Other (specify) _____
 - * Unknown

37. Is the Child Receiving Specialized Visual Impairment Services? If the child receives specialized visual impairment services, check **“yes”** and indicate the type of service received. Specialized visual impairment/early intervention services include those programs focused on serving young blind and visually impaired children whose services are provided by a certified teacher of students with visual impairment, a deaf/blind specialist, or orientation and mobility specialist or other specially trained personnel. (Check **all** that apply). If **“no”**, skip to item #40.

Direct services are those where the teacher is working with the child and/or family. There **must be** teacher/child contact.

Consultant services are those where the teacher provides input about the child to the adults in the program. There is minimal child contact.

38. Where Are Specialized Visual Impairment Services Provided? Indicate where the child receives specialized visual impairment services. Please check **all** that apply.
39. Who Provides Specialized Visual Impairment Services? If the vision service provider is certified in a specific visual related field, please indicate that field. If not, please indicate the service provider’s certification or training under “other.” Check **all** that apply.
40. Does the Child Receive Related Services? Identify **all** related services from any source. Indicate “no” if the child does not. Indicate “unknown” if you are not sure.

PROGRAM UPDATE INFORMATION

41. Child’s Current Status: Indicate the current status of services provided to the child. Important to indicate the child’s current status, please.

TRANSITIONAL INFORMATION

This section is to be completed when the child leaves your program for any reason.

42. What Type of Program did the Child Transition into at Age Three? Indicate the type of program the child transitioned into at age three. **Check only one.**
43. Visually Impaired Specialized Services: Will the child receive visually impaired specialized services in new setting?
44. Program Exit Date: Indicate month/day/year child terminated your Program

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