

# BABIES COUNT

## The National Registry for Children with Visual Impairments, Birth to 3 Years

### INSTRUCTIONAL MANUAL

- Survey is to be completed at entry to the program providing vision services AND at exit from the program.
  - At entry, complete Sections A, B, and C.
  - At exit, complete ALL sections.
  - IF child RE-ENTERED program after an exit, then complete the RE-ENTRY section ONLY. Also use the same child code, so as not to duplicate data.
  - Please complete all items.
- The survey is to be completed by a service provider and not to be given to a parent/guardian to be completed.
- If there is any information that parents/guardians do not feel comfortable sharing, or seems too personal to them, they are not required to answer.

#### **Section A: Child and Family Information**

Complete this section at both **ENTRY** and **EXIT** of program.

##### **Information about the child:**

1. Gender: Indicate child's gender.
2. Ethnicity of child: Check the box that represents the child's ethnic origin. You may check all that apply if child is of mixed ethnicity. If you select "other", please indicate ethnicity in writing.
3. Location of primary residence: Indicate the zip code where the child currently lives.
4. Date of Birth: Indicate date child was born by month/day/year. Use 2 digits for day and month (for example, 06 for 6<sup>th</sup> day and 06 for month of June) and 4 digits for the year (2014).
5. 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" is considered 38 weeks gestation or older. Seek this information first from the medical record, if available. If not available, ask parents.
6. Birth Weight: Indicate child's weight at birth in grams (preferred) or pounds and ounces. Seek this information first from the medical record, if available. If not available, ask parents.
7. Multiple Birth: Indicate if this child was the product of a multiple birth or pregnancy.

## Information about Parents or Guardians:

Sometimes these questions regarding information about the parents or guardians are personal and sensitive. Please note that if the family is uncomfortable in answering, they do not have to answer, however they should be asked. The person completing the survey can ask questions in a culturally responsible manner with a matter of fact and non-judgmental way, which really depends on the family and the situation.

**One suggestion is to say, “I work with many types of families. The following questions are meant to give information about the diversity of families of children with visual impairments around the nation, however if any makes you feel uncomfortable, just let me know and we can move on. Remember, your name is not on this survey and nobody will identify you.”**

8. Age of Mother: Indicate the age of the *biological* mother at the time of the child’s birth.
9. Age of Father: Indicate the age of the *biological* father at the time of the child’s birth.
10. Child currently resides primarily with: Indicate all persons with whom the child **currently lives with** in the same dwelling (house, apartment, etc.). 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 (who the child LIVES with), indicate number.
11. Primary language spoken in the home: Indicate if English is the language used **most often** in the home. If more than one language is spoken equally in the home, then a judgement call should be made as to whether the child is exposed to enough English to be considered “primary”.
12. Level of education completed: Indicate highest level of education completed by both parents/guardians who live with the child. If you indicate grade completed, you must indicate the highest grade completed if known.

## **Section B: Medical and Visual Impairment Information**

**Complete this section at both ENTRY and EXIT from program.**

Questions #14 through #27 should be completed with information obtained by medical records, whenever possible.

Questions #28 through #32 are observations of functional vision and can be obtained through direct observation of the child by the educational vision professional or interviews with the parent.

13. It is preferred that visual diagnosis is obtained by medical reports. However there are instances where a diagnosis is suspected or unconfirmed and can be reported by the parent. Please indicate the source of visual diagnosis information, either from the medical reports or the parent.
14. Please indicate the date (preferred) OR age of child when the visual diagnosis was diagnosed. In the instances that the diagnosis is only suspected or unconfirmed, no date can be given, therefore check "diagnosis is suspected".

Information in questions #15-18 **must or preferred** to be obtained from medical reports. Stars appear where the visual condition cannot be considered a primary or additional diagnosis. For example, albinism is never considered an additional or secondary diagnosis, so no box is given. Also amblyopia is never considered a primary diagnosis, so no box is given.

- For each eye, check **only one** condition under "primary" and all that apply under "additional".
  - If the child has two primary diagnoses, then use professional judgment to determine which of the two is primary.
  - If the diagnosis is unknown and a doctor has examined the child, then indicate "unknown and examined".
  - If the eye condition is truly "unknown" and a doctor has not yet examined the child, indicate unknown. It would be important to help assist the family in locating a pediatric ophthalmologist to diagnosis the visual impairment.
15. 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**.
  16. Additional diagnosis (left eye): Indicate additional visual diagnosis in the child's left eye as determined by a medical report. Check **all** that apply.
  17. 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**.
  18. Additional diagnosis (right eye): Indicate additional visual diagnosis in the child's right eye, as determined by a medical report. Check **all** that apply.
  19. Etiology of the documented or suspected visual impairment. Indicate the etiology or "cause" of the visual impairment. Often the exact timing of occurrence of cause of visual impairment is "unknown". For instance, it may be unknown, even by the neonatologist,

when the stroke happened that caused the CVI as it could of happened in utero or during birth. In cases such as these, indicate “unknown” as it truly may be unknown.

Etiology	Description	
<b>Prenatal</b>	Factors attributed to the visual impairment that occurred <b>BEFORE</b> birth. Typically these factors are genetic or chromosomal, or a structural birth defect, however they may also involve complications that occur during pregnancy.	
	Dominant, recessive and X-linked inheritance traits	Child has a family member with the same condition such as congenital cataracts, glaucoma or aniridia
	Chromosomal abnormality	Child’s visual diagnosis is part of a genetic or chromosomal condition, such as CHARGE
	Midline brain abnormality	Child’s mid brain was not developed properly, such as optic nerve hypoplasia/septo optic dysplasia.
	Ocular structure abnormality	Child’s ocular structures did not develop properly such as micro/anophthalmia or coloboma
	Complications during pregnancy	Maternal infection such as CMV or preeclampsia
<b>Perinatal</b>	Factors attributed to the visual impairment that occurred <b>DURING</b> or <b>IMMEDIATELY</b> after birth.	
	Prematurity	The child is a premature infant (37 weeks gestation or earlier and/or weighed less than 2500 grams) and developed retinopathy of prematurity (ROP) or other visual/neurologic conditions directly related to their prematurity (such as IVH or PVL).
	Complications of delivery/birth injury	Circumstance where the child experienced a lack of oxygen, or injury that caused damage to the brain. Also the child may have had very low Apgar scores at birth.
	Neonatal infection	Child acquired an infection during birth that caused damage to either brain or ocular structures.
<b>Postnatal</b>	Factors attributed to the visual impairment that occurred <b>AFTER</b> birth/delivery (after the child and family leaves the hospital) and during childhood. If this etiology is chosen, please indicate if visual impairment was caused by a non-accidental trauma. (#21)	
	Non-accidental trauma (NAT)	Sometimes referred to as Shaken Baby Syndrome.
	Anoxia/Asphyxia/Hypoxia	Circumstance where the child experienced a lack of oxygen, or injury that caused damages to the brain such as due to a near-drowning or choking

		incident.
	Tumors	Child has or had a tumor (both cancerous or non cancerous), either in the eye or visual pathways in the brain, which has affected the visual system.
	Brain Disorder	Child is experiencing a disorder where the brain is in a degenerative state or hydrocephalus where the intracranial pressure is elevated due to shunt malfunction.
	Trauma	Child experienced a circumstance of trauma that caused damage to the visual system. Trauma is different than a lack of oxygen or Shaken Baby Syndrome, such as car accident or injury to eye.
	Childhood illness/infection	Child experienced an illness (such as meningitis) or infection (viral) that caused damage to eye structures or visual pathways in brain

20. If the etiology is postnatal, is the visual impairment due to a non-accidental trauma (Shaken Baby Syndrome)? Answer this question either yes, no, or not postnatal. Only answer yes if a doctor has clearly determined it. If the answer to this question is unknown, then indicate "unknown".
21. The child has been prescribed corrective lenses for a refractive error (glasses or contacts) or prostheses. If so, indicate the type. If the child has been prescribed glasses or contacts, but does not wear them, please indicate that they have them.
22. Additional medical and health conditions: Please indicate other medical and health impairments, which are included in the health records of the child. Check all that apply.

Medical or Health Condition	Description
Allergies	Child has an allergy to any substance, such as food, medication, or nature allergen.
Cancer	Child has been diagnosed with a tumorous cancer anywhere in the body.
Endocrine Disorder	Child has been diagnosed with an endocrine disorder and is on a hormonal replacement or treatment plan (such as septo optic dysplasia or diabetes)
Feeding Problems	Child may have a diagnosis of "failure to thrive", or is not able to take nutrition through mouth and using a feeding tube (either nasal or gastrostomy)
Heart Disorder	Child has been diagnosed with one of many heart conditions and either had surgery to correct or corrected on its own.

Respiratory Problem	Child has been diagnosed with one of many respiratory issues and receives medical treatments (such as medication or regular breathing treatments)
Technology Dependent	Child has equipment (feeding machines, breathing machines, oxygen, hearing aides or cochlear implants, etc.) needed for medical issues.
Autism Spectrum Disorder	Child has an official diagnosis of ASD, NOT suspected.
Cerebral Palsy	Child has an official diagnosis of CP, NOT suspected.
Deaf or Hearing Impaired	Child has an official diagnosis of HI, NOT suspected.
Orthopedic Impairment	Child has a diagnosis of an orthopedic impairment that is NOT Cerebral Palsy, such as arthrogryposis, congenital anomaly (club foot or absence of limb), or a disease of the bone.
Seizure Disorder/Infantile Spasms	Child has any type of seizure disorder and takes medication or other medical treatment to control.
Other	Child's medical conditions are not included in the above list. Please write in what conditions they are if they cannot be included in the other categories.
None	Child has no other health or medical conditions in addition to their vision condition.

23. Presence of additional developmental delays: Indicate if child has delays in other developmental areas. These should be determined by professional evaluations completed at the entry to early intervention services and not your personal opinion. If child has not yet had a multi-disciplinary evaluation to determine additional delays, please indicate, "not yet determined".

**Summary of child:**

24. Functional Vision  
This child's use of functional vision can best be described by **ONE** of the following. Determination should be obtained by review of medical records (eye report by pediatric ophthalmologist) OR by professional judgment of the educational vision profession with the use of a functional vision assessment rather than measured visual acuities.

Functional Vision	Description
Normal or near normal visual functioning	This visual classification should be used if, at this time, the child's vision is normal for the age of the child, or the child has a progressive loss, or the child's vision

	appears to be normal however it should be monitored.
Low Vision	In general, children with low vision have a visual condition, which limits their visual acuity to 20/70 to 20/200 with correction. While often children under the age of 3 are not able to have their acuities tested with accuracy, typically children with low vision will use vision as their primary learning channel though vision is impaired compared to their peers with typical sight.
Meets the definition of blindness	While all states have different definitions of blindness for educational purposes, the definition of "legal blindness" is a visual acuity with correction of 20/200 or worse or a 20° visual field. Again, children under 3 may not be able to have with visual acuities tested with accuracy, however children who meet the definition of blindness will generally use their use of touch or hearing as primary learning media and vision is secondary.
Functions at the definition of blindness	Children with this visual classification generally have neurological vision impairment rather than an ocular condition. It is possible to have normal visual acuity but demonstrate functional vision behaviors to suggest a significant visual impairment.

25. Developmental Summary

This child's overall developmental needs can best be described by **ONE** of the following. Determination should be obtained by review of multi-disciplinary evaluations OR by professional judgment of the educational vision profession with the use of a formal observational testing protocol, such as The Oregon Project.

Developmental Need	Description
Typical development	Child is developing typically yet may have a few discrepancies which are typical or expected for a child with a significant visual impairment. Generally these children require no additional supports beyond the educational vision professional for their overall developmental needs.
Mild to moderate support needs	Child has mild to moderate developmental delays and receives additional support through other professionals such as OT, PT or SLP.
Intensive support needs	Child has severe developmental needs and needs extensive supports from a multi-disciplinary team including the above

	supports, with the inclusion of possible nursing care due to medical needs.
--	---

26. Primary Learning Channel

This child's primary learning channel can best be described by **ONE** of the following. Determination should be obtained by professional judgment of the educational vision professional with the use of observations of child or interview with parents regarding learning channels.

Primary Learning Channel	Description
Visual	Child generally uses their vision as a primary means of obtaining information from their environment including play and social interaction, with hearing and touch as secondary.
Tactual	Child generally uses their touch as a primary means of obtaining information from their environment including play and social interaction, with hearing and vision as secondary.
Auditory	Child generally uses their hearing as a primary means of obtaining information from their environment including play and social interaction, with vision and touch as secondary.

### Section C: Early Intervention Service Information

Complete this section at both ENTRY to and EXIT from program.

27. Referral Date: Indicate the date the child was REFERRED to your program for vision services.
28. Enrollment Date: Indicate the date the child was ENROLLED to your program for vision services and service begun.
29. Family Referred for Vision Services by: Indicate who initially referred the family to the agency for vision services. Check **one** box and identify the referral source. Please do not give names.

Referral Source	Description
Medical Provider	Ophthalmologist, optometrist, neurologist, pediatrician or social worker through hospital
Public Agency	Child was referred through the state's formalized Child Find process such as Interagency Council or State Part C lead agency.
Early Intervention Program	Specific EI program that provides direct services to children and families, such as Easter Seals, United



	Cerebral Palsy, or a staff person from this program.
Family/Friend	Non-professional person in the life of the child. This includes the parents themselves.
Other	Another referral source that does not fit in the above categories. Please specify this person's role in the life of the child but not their name.
Unknown	It is unknown how the child was referred to program for vision services.

30. **WHO?** (Professional who provides the specialized vision services): Indicate the job title and qualifications of the professional who is providing specialized VI services to the child and family. Check **all** that apply.

Professional	Description of Qualifications
State licensed teacher of Students with Visual Impairments (TVI)	Certified and licensed teacher of students with visual impairments in the state the teacher resides. Teacher completed a qualified university teacher preparation program in the area of education for the visually impaired.
Non-VI licensed professional employed and trained by specialized program for VI	Professional is not licensed in the area of vision by the state department of education, however may have another professional license such as special education, physical or occupational therapy, or speech pathology. This professional is employed and trained by a specialized program for VI to provide specialized VI services for <u>only</u> the program of which they are employed.
Certified Orientation & Mobility Specialist (COMS)	Professional completed a qualified university preparation program for orientation and mobility. They hold ACVREP certification in the area of orientation and mobility.
Deaf/Blind Specialist	Professional is state licensed in education for the visually impaired, deaf or hard of hearing, both VI and D/HH, special education for the children with multiple disabilities and severe sensory impairments, or any combination of the above. The state's federally funded Deaf/Blind Project generally employs them.
Other	Please specify the qualification or job title of the professional providing specialized VI services if they do not fit in the above categories (example may be Certified Low Vision Therapist (CLTV).

31. **WHAT?** (Frequency of ongoing specialized vision services): Indicate the frequency the child and family will be receiving specialized vision services from the specialized vision services provider.

32. **WHERE? (Location of Specialized VI Services):** Indicate the location or setting of the specialized visual impairment services. Please check **all** that apply.

Location of VI Services	Description
Home	Child's primary residence in the presence of the parents/guardians.
Specialized VI/EI Program	Center-based program where child and family attend to receive specialized vision services. This program only provides services for children with visual impairments.
Early Intervention Center	Center-based early intervention program for all children with disabilities, including those with visual impairments. Child and family attend to receive a range of services, including specialized VI services.
Day Care Center	Child attends a day care center for all children with and without disabilities while their parents/guardians are at work or school. Parents/guardians may or may not be in attendance during specialized VI services in this setting.
Family/Home Day Care	Child attends a home day care for all children with and without disabilities or the home of another family member (grandmother or aunt, for example) while their parents/guardians are at work or school, typically in a private residence. Parents/guardians may or may not be in attendance during specialized VI services in this setting.
Hospital	Child is in the hospital and specialized VI services are provided with or without attendance by parents/guardian.
Residential Care Facility	Child is in a hospital-like care facility, typically a long-term care facility but may be a residential type setting. Parents/guardians do not reside with the child, however may be present during specialized VI services.
Medical visits with family only	Professional providing specialized VI services to child and family accompany them to medical visits to pediatric ophthalmologist or other medical appointments requested by family.
Other	Please specify the setting specialized VI services will be provided if not included in the above choices.

33. **Additional early intervention services?** Identify **all** related early intervention services, in addition to the specialized VI services, as indicated on the child and family's current IFSP. Indicate "no" if the child does/did not receive other services. Indicate "unknown" if you are not sure. These services will be listed on the child and family's IFSP.

## Section D: Program Exit Information

Complete this section at **EXIT** from program **ONLY**.

34. Date of Exit: Indicate the date the child was officially exited or was withdrawn from receiving specialized VI services. Use 2 digits for day and month (for example, 06 for the 6<sup>th</sup> day or month of June) and 4 digits for the year (2014).
35. Reason for Exit: Indicate the reason the child was exited or withdrawn from receiving specialized VI services.

Reason for Exit	Description
Turned 3 years of age.	Child turned 3 years old and is not eligible to continue with early intervention services.
Moved	Child and family moved out of the area. Their services from the agency providing specialized VI services may have ended, but may also be started up by another agency and program. If this occurs, please contact new receiving agency (if known) regarding Babies Count information.
No longer in need of specialize VI services	Child's visual impairment status may have changed and child does not meet the continued eligibility to receive specialized VI services.
Parent refused services	Parent/guardian made the decision to discontinue specialized VI services for a variety of reasons. If parent decides to start services at a later date, follow re-entry procedures.
Unable to contact family	Family's contact status changed and is not able to be located to provide services. If family is located at a later date, follow re-entry procedures.
Deceased	Child has died.
Other	Specify the reason child was exited out of services, if reason is not included in the above categories.

36. Type of Program Child Transitioned into after Leaving Program **IF THEY TURNED 3**: When a child turns 3, early intervention services end, however special education or other educational services may begin. Indicate they type of educational programming child will participate in after they leave early intervention. You may check all that apply as quite often child participate in multiple programs.

Educational Program	Description
Community Preschool Classroom	Child will attend school in a classroom in Head Start or a private preschool program

	with peers who are typically developing.
Day Care Setting	Child will attend a day care center or setting while their parents/caregivers are at work or school.
Public School Special Education Preschool Classroom	Child will attend school in a special education preschool classroom in the public school. Other students may be typically developing or have a variety of special needs.
Public School Special Education Preschool Classroom for Students with VI	Child will attend school in a special education preschool classroom in the public school and the classroom is designed only for students with VI.
Day School/Preschool for Students with VI in a Specialized VI Program or Agency	Child will attend school at a specialized program or agency designed for children with VI only.
Home Based Special Education Services	Child will not attend a center-based school program, but will have teachers/therapists visit them in their home according to their IEP. Generally services are provided in the home due to medical necessity.
Home School	Family has decided to forgo public school district services and will provide home schooling to child at home. Generally a parent acts as "teacher" for part of the day.
Pediatric Health Care Facility	Child will receive educational services in the residential medical facility they reside due to medical necessity.
Unknown	It is not known what educational programming is planned for the child when they turned 3.
Other	Please specify setting for educational programming if it does not fit in any of the above categories. This includes if family has forgone any educational programming for the child.

37. Specialized VI Preschool Services in New Setting: This information can be obtained from the child's IEP, which is written when a child turns 3, or from the parent. If specialized VI services (such as services from a TVI or COMS) will be provided in their new preschool program, check "yes". If NO specialized VI services will be provided, check "no". If it is unknown, check "unknown".