BABIES COUNT

DATA COLLECTION FORM

The National Registry for Children with Visual Impairments

Birth to 3 Years

**BASIC INSTRUCTIONS:**

**Every question should be answered, even if unknown**

* Please refer to instructional manual for additional information or points of clarification for any items on this survey form.
* The survey is to be completed by **a provider of specialized VI services** 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.
* Survey is to be completed at **entry** to the program providing specialized vision services **AND** at **exit** from the program.
	+ **At entry, complete Sections Pre A, A, B, and C.**
	+ **At exit, complete ALL sections (B, C, & D).**

**Section Pre A: CHILD and FAMILY INFORMATION**

1. Gender (Choose **only** one):

 ☐ Male

 ☐ Female

2. Date of Birth: Month\_\_\_\_\_\_ Day\_\_\_\_\_\_ Year\_\_\_\_\_\_

3. Birth weight (Choose **only** one):

☐ Weight in \_\_\_\_ (grams)

☐ Weight in \_\_\_\_ (pounds)

☐ Unknown

**Section A CHILD and FAMILY INFORMATION**

**Information about the child:**

4. Ethnicity of child (check **all** that apply):

☐ Caucasian/White ☐ African American/Black ☐ Native Alaskan/American Indian

☐ Asian ☐ Hispanic/Latino ☐ Pacific Islander

☐ Other\_\_\_\_\_\_\_\_\_ ☐ Unknown ☐ Middle Eastern/North African

☐ Declined to Answer

1. Gestational age at birth (Choose **only** one):

☐ Age in Weeks \_\_\_\_\_

☐ Full Term - 38 weeks

☐ Unknown

6**.** Is this child part of multiple births? (Choose **only** one):

☐ No

☐ Twins

☐ Triplets

☐ Other\_\_\_\_\_\_\_\_\_\_\_\_

**Information about parents/guardians**

7. Biological mother’s age at the birth of child (Choose **only** one):

 ☐ Age\_\_\_\_

☐ Unknown

☐ Declined to answer

8. Biological father’s age at the birth of child (Choose **only** one):

☐ Age\_\_\_\_

☐ Unknown

☐ Declined to answer

9. Child currently resides primarily with (check **all** persons currently living with child):

☐ Declined to answer

Mother ☐ Biological ☐ Foster ☐ Adoptive ☐ Step

2nd Mother ☐ Biological ☐ Foster ☐ Adoptive ☐ Step

Father ☐ Biological ☐ Foster ☐ Adoptive ☐ Step

2nd Father ☐ Biological ☐ Foster ☐ Adoptive ☐ Step

Grandmother ☐ Maternal ☐ Paternal

Grandfather ☐ Maternal ☐ Paternal

Other Adult ☐ Related ☐ Unrelated

Siblings ☐ \_\_\_\_\_\_\_\_\_ (how many)

10. Is English the primary language spoken in home? (Choose **only** one)

☐ Yes

☐ No

☐ Declined to answer

11. Level of education completed by parent/guardian: (check **all** that apply):

Mother: Father:

☐ Highest Grade Completed\_\_\_\_\_ ☐ Highest Grade Completed\_\_\_\_\_

☐ High School Diploma or GED ☐ High School Diploma or GED

☐ Some College ☐ Some College

☐ Associate Degree ☐ Associate Degree

☐ Bachelor’s Degree ☐ Bachelor’s Degree

☐ Some Graduate Courses ☐ Some Graduate Courses

☐ Graduate Degree ☐ Graduate Degree

☐ Unknown ☐ Unknown

☐ Declined to answer ☐ Declined to answer

**Section B: MEDICAL and VISUAL INFORMATION**

Complete this section at both **entry** and **exit.**

12. The visual diagnosis information was obtained by (Choose **only** one):

☐ Medical records

☐ Parent report

13. Date of visual diagnosis **OR** age (in nearest whole month) at the time of diagnosis (Choose **only** one):

 ☐ Month\_\_\_\_\_\_ Day\_\_\_\_\_\_ Year\_\_\_\_\_\_

☐ \_\_\_\_\_Age (in months)

☐ Diagnosis is suspected and not yet officially diagnosed by a doctor.

14 – 17. **Visual diagnosis:** **Right Eye Left Eye**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **14. Primary**Check only **one** | **15. Additional**Check **all** that apply | **16.** **Primary**Check only **one** | **17. Additional**Check **all** that apply |
| Albinism | ☐ | \* | ☐ | \* |
| Amblyopia | \* | ☐ | \* | ☐ |
| Aniridia | ☐ | \* | ☐ | \* |
| Anophthalmia | ☐ | \* | ☐ | \* |
| Aphakia | ☐ | ☐ | ☐ | ☐ |
| Cataracts (corrected and uncorrected) | ☐ | ☐ | ☐ | ☐ |
| Chorioretinitis | ☐ | ☐ | ☐ | ☐ |
| Coloboma | ☐ | ☐ | ☐ | ☐ |
| Corneal Defects/Peter’s Anomaly | ☐ | \* | ☐ | \* |
| Cortical Visual Impairment (CVI) | ☐ | ☐ | ☐ | ☐ |
| Delayed Visual Maturation | ☐ | ☐ | ☐ | ☐ |
| Enucleation | ☐ | \* | ☐ | \* |
| Familial Exudative Vitreoretinopathy (FEVR) | ☐ | \* | ☐ | \* |
| Glaucoma | ☐ | ☐ | ☐ | ☐ |
| Hemianopsia/Hemianopia | ☐ | ☐ | ☐ | ☐ |
| Leber’s Congenital Amaurosis | ☐ | \* | ☐ | \* |
| Microphthalmia | ☐ | ☐ | ☐ | ☐ |
| Nystagmus, Congenital Motor | ☐ | ☐ | ☐ | ☐ |
| Oculomotor Apraxia & Eye Movement Disorders | ☐ | ☐ | ☐ | ☐ |
| Optic Atrophy | ☐ | ☐ | ☐ | ☐ |
| Optic Glioma | ☐ | ☐ | ☐ | ☐ |
| Optic Nerve Hypoplasia (ONH)  | ☐ | \* | ☐ | \* |
| Persistent Hyperplasia of the Primary Vitreus (PHPV) | ☐ | ☐ | ☐ | ☐ |
| Ptosis | ☐ | ☐ | ☐ | ☐ |
|  Refractive Errors  | \* | ☐ | \* | ☐ |
| Retinal Disorder-non specific | ☐ | ☐ | ☐ | ☐ |
| Retinitis Pigmentosa (RP) | ☐ | \* | ☐ | \* |
| Retinoblastoma | ☐ | \* | ☐ | \* |
| Retinopathy of Prematurity (ROP) | ☐ | ☐ | ☐ | ☐ |
| Rod/Cone Dystrophies | ☐ | \* | ☐ | \* |
| Strabismus | \* | ☐ | \* | ☐ |
| Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | ☐ | ☐ | ☐ | ☐ |
| Unknown and examined/tested by a doctor | ☐ | ☐ | ☐ | ☐ |
| Unknown, NOT examined or tested by doctor  | ☐ | ☐ | ☐ | ☐ |
| no additional diagnosis | \* | ☐ | \* | ☐ |

18. Occurrence of etiology of documented or suspected visual impairment (Choose **only** one):

☐ Prenatal- Before birth

☐ Perinatal- During birth or immediately after birth

☐ Postnatal- After birth or after the child leaves the hospital

☐ Unknown

19. Is the visual impairment due to a **non-accidental trauma (NAT),** also including Shaken Baby Syndrome? (Choose **only** one):

☐ Yes

☐ No

☐ Unknown

20. The child currently has one or more of the following: (check **all** that apply):

 ☐ Glasses ☐ Prosthesis (one eye or both)

 ☐ Contact Lenses ☐ None of the above

21. Additional medical and health conditions (check **all** that apply):

☐ Allergies ☐ Autism Spectrum Disorder

☐ Cancer ☐ Cerebral Palsy

☐ Endocrine Disorder ☐ Deaf or Hard of Hearing

☐ Feeding Problems ☐ Orthopedic Impairment

☐ Heart Disorder ☐ Seizure Disorder/Infantile Spasms

☐ Respiratory Problems ☐ Technology Dependent

☐ Other Medical or Health Conditions: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

☐ None

22. Presence of additional developmental delays (check **all** that apply):

☐ Cognitive Delays ☐ Language Delays

☐ Fine Motor Delays ☐ Gross Motor Delays

☐ Social Skills Delays ☐ Adaptive Skills Delays

☐ None or not yet determined

**Summary of child:**

23. This child’s functional vision can best be described as: (choose **only** one)

☐ Normal or near normal visual functioning

☐ Low Vision

 ☐ Meets the definition of blindness

 ☐ Functions at the definition of blindness

24. This child’s overall developmental needs can best be described as: (choose **only** one)

 ☐ Typical development

 ☐ Mild to moderate support needs

 ☐ Intensive support needs

25. This child’s primary learning channel can best be described as: (choose **only** one)

 ☐ Visual

 ☐ Tactual

 ☐ Auditory

☐ Unknown

**Section C: EARLY INTERVENTION SERVICE INFORMATION**

**Complete this section at both entry and exit.**

26. Postal zip code of primary residence: \_\_\_\_\_\_\_\_\_\_\_\_

27. Date of **referral** to program for specialized vision services: M \_\_\_\_\_ D\_\_\_\_\_ Y\_\_\_\_\_

28. Date of **enrollment** to program for specialized vision services: M \_\_\_\_\_ D \_\_\_\_\_ Y \_\_\_\_\_

29. Family referred for specialized vision services by (choose **only** one):

 ☐ Medical Provider (indicate specialty) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 ☐ Child Find / Public Agency

 ☐ Early Intervention Program

 ☐ Family/Friend

 ☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 ☐ Unknown

30. **Who** is/was providing specialized vision services to the child and family? (Check **all** that apply):

☐ State licensed teacher of students with visual impairments

☐ Other licensed professional employed and trained by specialized program for VI

☐ Certified Orientation & Mobility Specialist

☐ Deaf/Blind Specialist

☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

☐ No ongoing specialized VI services provided to child and family

31. **What** frequencyof ongoing specialized vision services will be/were provided to the child and family? (Choose **ONLY** one):

 ☐ Weekly specialized VI services to family and team

 ☐ Bi-weekly specialized VI services to family and team

 ☐ Monthly specialized VI services to family and team

 ☐ Quarterly specialized VI services to family and team

 ☐ Annual specialized VI services to family and team

 ☐ Consultation specialized VI services only as needed when requested

 ☐ One time evaluation only

 ☐ Other (Specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

32. **Where** are/were specialized vision services provided? (Check **al**l that apply):

 ☐ Home ☐ Family/Home Day Care (or other community environments)

 ☐ Specialized VI/EI Program ☐ Hospital

 ☐ Early Intervention Center ☐ Residential Care Facility

 ☐ Day Care Center ☐ Medical visit with family

☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

☐ No ongoing specialized VI services provided to child and family

33. Which additional early Intervention service(s) does/did the child and family receive? (Check **all** that apply):

 ☐ Developmental Special Instruction ☐ Psychological Services

☐ Occupational Therapy ☐ D/HH Services/Audiology

 ☐ Physical Therapy ☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_

 ☐ Speech/Language Pathology Services ☐ No other services

☐ Social Work Services ☐ Unknown

**Section D: PROGRAM EXIT INFORMATION**

Complete this section at **EXIT only**.

**Transitional Information:**

34. Date of **exit** from the program for specialized VI services: M \_\_\_\_\_ D\_\_\_\_\_ Y\_\_\_\_\_

35. Reason child exited specialized VI services (Choose **only** one):

☐ Turned three years of age

☐ Moved

☐ No longer in need of specialized VI services

☐ Parent declined services

☐ Unable to contact family

☐ Deceased

☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

36. If child exited from program at age 3, indicate type of program child transitioned to: (Check **all** that apply.) (Only if question 35 has turned 3 checked)

☐ Community Preschool Classroom, including Head Start

☐ Day Care Setting

☐ Public School Special Education Preschool Classroom

☐ Public School Special Education Preschool Classroom for Students with VI

☐ Day-School/Preschool for Students with VI in a Specialized VI Program

☐ Home-Based Special Education Services

☐ Home School

☐ Pediatric Health Care Facility

☐ Unknown

☐ None

☐ Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

37. Will specialized VI services be provided to this child in new setting? (Choose **only** one):

 ☐ Yes

☐ No

☐ Unknown