

BABIES COUNT-- The National Registry for Children with Visual Impairments (Birth-3 years)
DATA COLLECTION FORM

Last Name: _____ First Name: _____

School District: _____ TVI: _____

Parent/Guardian Signature for Babies Count is on file at local school district: ___Yes ___No

BASIC INSTRUCTIONS: Every question should be answered, even if unknown

- 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):

- | | | |
|---|---|---|
| <input type="checkbox"/> Caucasian/White | <input type="checkbox"/> African American/Black | <input type="checkbox"/> Native Alaskan/American Indian |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Hispanic/Latino | <input type="checkbox"/> Pacific Islander |
| <input type="checkbox"/> Other_____ | <input type="checkbox"/> Unknown | <input type="checkbox"/> Middle Eastern/North African |
| <input type="checkbox"/> Declined to Answer | | |

5. 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:

- Highest Grade Completed _____
- High School Diploma or GED
- Some College
- Associate Degree
- Bachelor's Degree
- Some Graduate Courses
- Graduate Degree
- Unknown
- Declined to answer

Father:

- Highest Grade Completed _____
- High School Diploma or GED
- Some College
- Associate Degree
- Bachelor's Degree
- Some Graduate Courses
- Graduate Degree
- Unknown
- 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	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Amblyopia	*	<input type="checkbox"/>	*	<input type="checkbox"/>
Aniridia	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Anophthalmia	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Aphakia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cataracts (corrected and uncorrected)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chorioretinitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coloboma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Corneal Defects/Peter's Anomaly	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Cortical Visual Impairment (CVI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delayed Visual Maturation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enucleation	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Familial Exudative Vitreoretinopathy (FEVR)	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Glaucoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hemianopsia/Hemianopia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leber's Congenital Amaurosis	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Microphthalmia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nystagmus, Congenital Motor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oculomotor Apraxia & Eye Movement Disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optic Atrophy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optic Glioma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optic Nerve Hypoplasia (ONH)	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Persistent Hyperplasia of the Primary Vitreus (PHPV)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ptosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Refractive Errors	*	<input type="checkbox"/>	*	<input type="checkbox"/>
Retinal Disorder-non specific	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retinitis Pigmentosa (RP)	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Retinoblastoma	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Retinopathy of Prematurity (ROP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rod/Cone Dystrophies	<input type="checkbox"/>	*	<input type="checkbox"/>	*
Strabismus	*	<input type="checkbox"/>	*	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Unknown and examined/tested by a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unknown, NOT examined or tested by doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
no additional diagnosis	*	<input type="checkbox"/>	*	<input type="checkbox"/>

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
- Contact Lenses
- Prosthesis (one eye or both)
- None of the above

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

- Allergies
- Cancer
- Endocrine Disorder
- Feeding Problems
- Heart Disorder
- Respiratory Problems
- Other Medical or Health Conditions: _____
- None
- Autism Spectrum Disorder
- Cerebral Palsy
- Deaf or Hard of Hearing
- Orthopedic Impairment
- Seizure Disorder/Infantile Spasms
- Technology Dependent

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

- Cognitive Delays
- Fine Motor Delays
- Social Skills Delays
- None or not yet determined
- Language Delays
- Gross Motor Delays
- Adaptive Skills Delays

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** frequency of 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 **all** that apply):

- | | |
|--|---|
| <input type="checkbox"/> Home environments) | <input type="checkbox"/> Family/Home Day Care (or other community environments) |
| <input type="checkbox"/> Specialized VI/EI Program | <input type="checkbox"/> Hospital |
| <input type="checkbox"/> Early Intervention Center | <input type="checkbox"/> Residential Care Facility |
| <input type="checkbox"/> Day Care Center | <input type="checkbox"/> 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):

- | | |
|---|--|
| <input type="checkbox"/> Developmental Special Instruction | <input type="checkbox"/> Psychological Services |
| <input type="checkbox"/> Occupational Therapy | <input type="checkbox"/> D/HH Services/Audiology |
| <input type="checkbox"/> Physical Therapy | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Speech/Language Pathology Services | <input type="checkbox"/> No other services |
| <input type="checkbox"/> Social Work Services | <input type="checkbox"/> 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