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

Last Name: _____ First Name: _____

School District: _____ TSVI: _____

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

Note: This survey collects information that will be entered anonymously into a data system which is accessed and managed solely by authorized account holders from each state or agency.

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):

☐ Caucasian/White	☐ African American/Black	☐ Native Alaskan/American Indian
☐ Asian	☐ Hispanic/Latino	☐ Pacific Islander
☐ Other_____	☐ Unknown	☐ Middle Eastern/North African
☐ 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:	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
    ☐ 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
    ☐ Autism Spectrum Disorder
    ☐ Cerebral Palsy
    ☐ Deaf or Hard of Hearing
    ☐ Orthopedic Impairment
    ☐ Seizure Disorder/Infantile Spasms
    ☐ Technology Dependent
    ☐ Other Medical or Health Conditions: _____
    ☐ None

22. Presence of additional developmental delays (check **all** that apply):
    ☐ Cognitive Delays
    ☐ Fine Motor Delays
    ☐ Social Skills Delays
    ☐ Language Delays
    ☐ Gross Motor 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** 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):

☐ 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
☐ Occupational Therapy
☐ Physical Therapy
☐ Speech/Language Pathology Services
☐ Social Work Services
☐ Psychological Services
☐ D/HH Services/Audiology
☐ Other (specify) _____
☐ No other 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 the child exited from the program at age 3, indicate the type of program the 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 a new setting? (Choose **only** one):
    ☐ Yes
    ☐ No
    ☐ Unknown