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
   o 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.
   o 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.
   o Survey is to be completed at entry to the program providing specialized vision services AND at exit from the program.
      o At entry, complete Sections Pre A, A, B, and C.
      o 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
   - 2nd Mother
   - Father
   - 2nd Father
   - Grandmother
   - Grandfather
   - Other Adult
   - 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:

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<th>15. Additional Check all that apply</th>
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<td>Chorioretinitis</td>
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<td>Corneal Defects/Peter's Anomaly</td>
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<td>Cortical Visual Impairment (CVI)</td>
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<td>Delayed Visual Maturation</td>
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<td>Enucleation</td>
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<td>Glaucoma</td>
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<td>Hemianopsia/Hemianopia</td>
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<td>Leber's Congenital Anamroisis</td>
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<td>Microphthalmia</td>
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<td>Nystagmus, Congenital Motor</td>
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<td>Oculomotor Apraxia &amp; Eye Movement Disorders</td>
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<td>Optic Atrophy</td>
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<td>Optic Glioma</td>
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<td>Optic Nerve Hypoplasia (ONH)</td>
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<td>Persistent Hyperplasia of the Primary Vitreus (PHPV)</td>
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<td>Ptosis</td>
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<td>Refractive Errors</td>
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<td>Retinal Disorder-non specific</td>
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<td>Retinitis Pigmentosa (RP)</td>
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<td>Retinoblastoma</td>
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<td>Retinopathy of Prematurity (ROP)</td>
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<td>Rod/Cone Dystrophies</td>
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<td>Strabismus</td>
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<td>Other: ___________________</td>
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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)
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
   - Early Intervention Center
   - Day Care Center
   - Hospital
   - Residential Care Facility
   - Medical visit with 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 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