

# 2020-2021 RESULTS

## **Babies Count National Registry of Children with Blindness or Visual Impairment (BVI) - aged birth to 36 months**

Citation: Snyder, D., Rife, D., & Lyle, L. (2022). Babies Count National Registry of Children with Blindness or Visual Impairment, Aged Birth to 36 Months: 2020 and 2021 Results. Babies Count. <https://babiescount.org>

<b>Critical Ages of Diagnosis of Eye Condition, Referral to BVI Services, and Enrollment to BVI Services</b>	<b>Age of DX (mo)</b>	<b>Age of Referral (mo)</b>	<b>Age at Enrollment (mo)</b>
CVI/DVM	9.6	11.5	12.6
ONH	5.8	9.3	10.1
ROP	3.2	10.4	11.5
Albinism	4.8	10.2	11.4
Structural	3.4	8.1	8.9
Retinal	9.1	10.1	11.1
Other	8.6	13.3	14.2
Unknown/none	9.9	12.3	13.2
<b>All Eye Conditions</b>	<b>7.5</b>	<b>11.5</b>	<b>12.4</b>

Primary Eye Condition	n	%
Cortical/Cerbral Visual Impairment (CVI)	905	30.4%
Optic Nerve Hypoplasia (ONH)	267	9.0%
Retinopathy of Prematurity (ROP)	249	8.4%
Albinism	109	3.7%
Structural Eye Anomaly	203	6.8%
Retinal Condition (unspecified)	170	5.7%
Other	706	23.7%
Unknown/none	365	12.3%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>

Gestational Age (at birth)	n	%
Full Term	1556	52.3%
37 to 33 weeks	632	21.4%
32 to 28 weeks	247	8.3%
27 weeks or less	292	9.7%
Unknown	248	8.3%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>

Non-Accidental Trauma (NAT) Caused BVI	n	%
Not a NAT	2688	90.4%
NAT	137	4.6%
Unknown	149	5.0%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>

<b>Concurrent Medical Condition</b>	<b>n</b>	<b>%</b>
None	809	27.2%
Neurological	1884	63.3%
<i>Autism spectrum disorder (ASD)</i>	68	
<i>Cerebral palsy/orthopedic impairment</i>	741	
<i>Seizures</i>	691	
<i>Congenital brain disorder</i>	194	
<i>Acquired brain disorder</i>	179	
<i>Spina bifida</i>	12	
Global syndrome	368	12.4%
<i>Chromosomal disorder</i>	139	
<i>Hereditary/genetic disorder</i>	163	
<i>Cranio facial disorder</i>	51	
<i>Mitochondrial/metabolic disorder</i>	15	
Endocrine	177	6.0%
Deaf/hard of hearing	243	8.2%
Feeding Issues	964	3.2%
Other	1078	36.2%
<i>Respiratory problems</i>	469	
<i>Heart disease</i>	251	
<i>Technology dependent</i>	137	
<i>Allergies</i>	121	

<i>Kidney/Liver condition</i>	13	
<i>Born with addiction</i>	26	
<i>Cancer</i>	18	
<i>Gastroesophageal reflux disease (GERD)</i>	15	
<i>inter-utero viral infection</i>	16	
<i>Sleep issues</i>	6	
<i>Blood condition</i>	3	
<i>Skin condition</i>	3	
<b>Level of Vision</b>	<b>n</b>	<b>%</b>
Meets definition of blindness	398	13.4%
Functions at the definition of blindness	616	20.7%
Low vision	1144	38.5%
Typical or near typical	799	26.9%
Unknown/no report	17	0.5%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>
<b>Level of Support Needs</b>	<b>n</b>	<b>%</b>
Typical support needs	398	13.4%
Mild/moderate support needs	1455	48.9%
Intensive support needs	1105	37.2%
Unknown/no report	16	0.5%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>

<b>Primary Learning Channel</b>	<b>n</b>	<b>%</b>
Vision	1385	46.6%
Tactual	334	11.2%
Auditory	692	23.3%
Unknown/no report	563	18.9%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>
<b>State</b>	<b>n</b>	<b>%</b>
Arizona	24	0.8%
Colorado	47	1.6%
Iowa	44	1.5%
Indiana	138	4.6%
Kentucky	199	6.7%
Maryland	344	11.6%
Massachusetts	410	13.8%
Nebraska	22	0.7%
New Mexico	427	14.4%
North Dakota	27	0.9%
Northern California	261	8.8%
Southern California	80	2.7%
Utah	467	15.7%
Vermont	15	0.5%
Washington	438	14.7%
Wisconsin	31	1.0%
<b>Total</b>	<b>2974</b>	<b>100.0%</b>

<b>Transition</b>	<b>n</b>	<b>%</b>
<b>Reason for Exit</b>		
Turned 3/aged out	626	65.8%
Family moved	62	6.6%
No longer in need	157	16.5%
Parent declined/unable to contact	76	8.0%
Deceased	25	2.6%
Unknown/unreported/NA	5	0.5%
<b>Total</b>	<b>951</b>	<b>100.0%</b>
<b>Next/Receiving Program</b>		
Public school preschool program	417	43.9%
Preschool at agency/center for BVI	61	6.4%
Head Start or community preschool	71	7.5%
Home school	44	4.6%
Unknown/unreported/NA	341	35.9%
Continue Part C services	17	1.8%
<b>Total</b>	<b>951</b>	<b>100.0%</b>
<b>Specialized BVI Services in Next Program</b>		
Yes	474	49.8%
No	228	24.0%
Unknown/unreported/NA	249	26.2%
<b>Total</b>	<b>951</b>	<b>100.0%</b>