|  |
| --- |
| **Babies Count National Registry of Children with Blindness or Visual Impairment (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: 2021 Results*. Babies Count. http://babiescount.org |
|   | 2020 | 2021 | Combined |
| **Child Characteristics** | **n** | **%** | **n** | **%** | **n** | **%** |
|  |   |   |   |   |   |   |
| **Gender** |   |   |   |   |   |   |
| Male | 1153 | 54.6% | 473 | 54.7% | 1626 | 54.7% |
| Female | 957 | 45.4% | 391 | 45.3% | 1348 | 45.4% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Gestational Age** |   |   |   |   |   |   |
| Full Term | 1135 | 53.8% | 421 | 48.7% | 1556 | 51.2% |
| 37 to 33 weeks | 427 | 20.2% | 205 | 23.7% | 632 | 21.9% |
| 32 to 28 weeks | 184 | 8.7% | 63 | 7.3% | 247 | 8.0% |
| 27 weeks or less | 211 | 10.0% | 81 | 9.4% | 292 | 9.7% |
| Unknown | 153 | 7.3% | 95 | 11.0% | 248 | 9.1% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Multiple Birth** |   |   |   |   |   |   |
| Single | 1965 | 93.1% | 801 | 92.7% | 2766 | 92.9% |
| Twins | 138 | 6.5% | 63 | 7.3% | 201 | 6.9% |
| Triplets | 7 | 0.3% |   |   | 7 | 0.3% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Both Eyes Primary Eye Condition** |   |   |   |   |   |   |
| CVI/DVM | 634 | 30.0% | 271 | 31.4% | 905 | 30.7% |
| ONH | 197 | 9.3% | 70 | 8.1% | 267 | 8.7% |
| ROP | 196 | 9.3% | 53 | 6.1% | 249 | 7.7% |
| Albinism | 77 | 3.6% | 32 | 3.7% | 109 | 3.7% |
| Structural | 137 | 6.5% | 66 | 7.6% | 203 | 7.1% |
| Retinal | 119 | 5.6% | 51 | 5.9% | 170 | 5.8% |
| Other | 507 | 24.0% | 199 | 23.0% | 706 | 23.5% |
| Unknown/none | 243 | 11.5% | 122 | 14.1% | 365 | 12.8% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Non-Accidental Trauma (NAT)** |   |   |   |   |   |   |
| Not a NAT | 1991 | 94.4% | 697 | 80.7% | 2688 | 87.6% |
| NAT | 106 | 5.0% | 31 | 3.6% | 137 | 4.3% |
| Unknown | 13 | 0.6% | 136 | 15.7% | 149 | 8.2% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Concurrent Medical Condition** |   |   |   |   |   |   |
| None | 569 | 27.0% | 240 | 27.8% | 809 | 27.4% |
| Neurological | 1320 | 62.6% | 564 | 65.3% | 1884 | 64.0% |
| *Autism spectrum disorder (ASD)* | *47* |   | *21* |   | *68* |   |
| *Cerebral palsy/orthopedic impairment* | *528* |   | *213* |   | *741* |   |
| *Seizures* | *477* |   | *214* |   | *691* |   |
| *Congential brain disorder* | *146* |   | *48* |   | *194* |   |
| *Acquired brain disorder* | *115* |   | *64* |   | *179* |   |
| *Spina bifida* | *7* |   | *5* |   | *12* |   |
| Global syndrome | 230 | 10.9% | 138 | 16.0% | 368 | 13.5% |
| *Chromosomal disorder* | *101* |   | *38* |   | *139* |   |
| *Hereditary/genetic disorder* | *83* |   | *80* |   | *163* |   |
| *Cranio facial disorder* | *31* |   | *20* |   | *51* |   |
| *Mitochondrial/metabolic disorder* | *15* |   |   |   | *15* |   |
| Endocrine | 134 | 6.4% | 43 | 5.0% | 177 | 5.7% |
| Deaf/hard of hearing | 178 | 8.4% | 65 | 7.5% | 243 | 8.0% |
| Feeding Issues | 687 | 32.6% | 277 | 32.0% | 964 | 32.3% |
| Other | 770 | 36.5% | 308 | 35.6% | 1078 | 36.1% |
| *Respiratory problems* | *349* |   | *120* |   | *469* |   |
| *Heart disease* | *160* |   | *91* |   | *251* |   |
| *Technology dependent* | *106* |   | *31* |   | *137* |   |
| *Allergies* | *94* |   | *27* |   | *121* |   |
| *Kidney/Liver condition* | *2* |   | *11* |   | *13* |   |
| *Born with addiction* | *19* |   | *7* |   | *26* |   |
| *Cancer* | *14* |   | *4* |   | *18* |   |
| *Gastroesophageal reflux disease (GERD)* | *12* |   | *3* |   | *15* |   |
| *inter-utero viral infection* | *9* |   | *7* |   | *16* |   |
| *Sleep issues* | *5* |   | *1* |   | *6* |   |
| *Blood condition* |  |   | *3* |   | *3* |   |
| *Skin condition* |  |   | *3* |   | *3* |   |
|  |   |   |   |   |   |   |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| **Developmental Delayed Domains** |   |   |   |   |   |   |
| None | 309 | 14.6% | 159 | 18.4% | 468 | 16.5% |
| Cognitive | 1326 | 62.8% | 472 | 54.6% | 1798 | 58.7% |
| Language | 1451 | 68.8% | 542 | 62.7% | 1993 | 65.8% |
| Fine motor | 1402 | 66.4% | 580 | 67.1% | 1982 | 66.8% |
| Gross motor | 1538 | 72.9% | 597 | 69.1% | 2135 | 71.0% |
| Social | 1216 | 57.6% | 381 | 44.1% | 1597 | 50.9% |
| Adaptive | 1163 | 55.1% | 440 | 50.9% | 1603 | 53.0% |
|   |   |   |   |   |   |   |
| **Number of Developmental Delays**  |   |   |   |   |   |   |
| No delays | 309 | 14.6% | 159 | 18.4% | 468 | 16.5% |
| 1 delayed domain | 190 | 9.0% | 79 | 9.1% | 269 | 9.1% |
| 2 delayed domains | 165 | 7.8% | 90 | 10.4% | 255 | 9.1% |
| 3 delayed domains | 178 | 8.4% | 69 | 8.0% | 247 | 8.2% |
| 4 delayed domains | 169 | 8.0% | 86 | 10.0% | 255 | 9.0% |
| 5 delayed domains | 228 | 10.8% | 82 | 9.5% | 310 | 10.2% |
| All 6 development domains delayed | 871 | 41.3% | 299 | 35% | 1170 | 38.0% |
| **Total** | **2110** | **100%** | **864** | **100.0%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Level of Vision** |   |   |   |   |   |   |
| Meets definition of blindness | 283 | 13.4% | 115 | 13.3% | 398 | 13.3% |
| Functions at the definition of blindness | 452 | 21.4% | 164 | 19.0% | 616 | 20.2% |
| Low vision | 797 | 37.8% | 347 | 40.2% | 1144 | 39.0% |
| Typical or near typical | 578 | 27.4% | 221 | 25.6% | 799 | 26.5% |
| Unknown/no report |   |   | 17 | 2.0% | 17 | 2.0% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Level of Support Needs** |   |   |   |   |   |   |
| Typical support needs | 301 | 14.3% | 97 | 11.2% | 398 | 12.8% |
| Mild/moderal support needs | 1016 | 48.2% | 439 | 50.8% | 1455 | 49.5% |
| Intensive support needs | 793 | 37.6% | 312 | 36.1% | 1105 | 36.8% |
| Unknown/no report |   |   | 16 | 1.9% | 16 | 1.9% |
| **Total**  | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Primary Learning Channel** |   |   |   |   |   |   |
| Vision | 1039 | 49.2% | 346 | 40.0% | 1385 | 44.6% |
| Tactual | 226 | 10.7% | 108 | 12.5% | 334 | 11.6% |
| Auditory | 495 | 23.5% | 197 | 22.8% | 692 | 23.2% |
| Unknown/no report | 350 | 16.6% | 213 | 24.7% | 563 | 20.7% |
| **Total** | **2110** | **100%** | **864** | **100.0%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Age of Vision Condition Diagnosis (months)** |
| Average | 7.6 | 7.3 | 7.4 |
| Standard deviation | 7.4 | 7.3 | 7.3 |
| Sample size (n) | 1829 | 662 | 2491 |
| No diagnosis/or unknown date | 281 | 13.3% | 202 | 13.3% | 483 | 13.30% |
| Oldest | 36.2 | 33.6 | 34.9 |
| Youngest | 0 | 0 | 0 |
|   |   |   |   |   |   |   |
| **Age of Referral to Specialized Blind/Low Vision Services (months)** |
| Average | 10.8 | 12.1 | 11.5 |
| Standard deviation  | 8 | 8.3 | 8.2 |
| Sample size (n) | 2110 | 829 | 2939 |
| No accurate date reported |   |   | 35 | 4.1% | 35 | 1.2% |
| Youngest | 0 | 0 | 0 |
| Oldest | 34.7 | 45.1 | 39.9 |
|   |   |   |   |   |   |   |
| **Days Between Referral and Enrollment to Specialized Blind/Low Vision Services** |
| 30 days or less | 1443 | 68.4% | 621 | 71.9% | 2064 | 70.2% |
| Over 30 days  | 667 | 31.6% | 218 | 25.2% | 885 | 28.4% |
| Unknown |   |   | 25 | 2.9% | 25 | 2.9% |
| **Total** | **2110** | **100%** | **864** | **100%** | **2974** | **100.0%** |
|   |   |   |   |   |   |   |
| **Age of Enrollment to Specialized Blind/Low Vision Services (months)** |
| Average | 11.8 | 13 | 12.4 |
| Standard deviation | 8.1 | 8.5 | 8.3 |
| Sample size (n) | 2110 | 829 | 2939 |
| No accurate date reported |   |   | 35 | 4.10% | 35 | 1.2% |
| Youngest | 0 | 0 | 0 |
| Oldest | 43 | 48 | 45.5 |
|   |   |   |   |   |   |   |