☑ CEU Article

Severe Visual Impairments in Infants and Toddlers in the United States

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Structured abstract: *Introduction:* This article describes the most prevalent visual conditions and other demographic characteristics of 5,931 young children with severe visual impairments in 28 states in the United States, the largest sample reported to date. The information presented in this article can assist in planning and implementing programs. *Method:* The data were collected at the time of entry into specialized early intervention programs for young children with visual impairments through reviews of records, interviews, and direct observations. They were sent to Babies Count: The National Registry for Children with Visual Impairments, Birth to 3 Years at the American Printing House for the Blind. The data were collected and entered between January 2005 and April 2011. *Results:* Cortical visual impairment, retinopathy of prematurity (ROP), and optic nerve hypoplasia were the three most prevalent diagnoses. Approximately 60% were identified as being legally blind, and 65% had disabilities in addition to visual impairments. The mean age of the children at the time of diagnosis was 4.9 (SD = 5.7) months, referral to specialized programs was at 10.5 (SD = 7.8) months, and entry into specialized programs was at 11.6 (SD = 8.0) months. There was an average lag of 5.6 months between the diagnosis and referral. *Discussion:* Cortical visual impairment, ROP, and optic nerve hypoplasia continue to be the leading causes of severe, uncorrectable visual impairments in children in the United States. ROP appears to be decreasing in prevalence; however, more children with ROP appear to have additional disabilities. The lag of 5.6 months between diagnosis and referral, a longer lag than was previously reported, is of concern. *Implications for practitioners:* Information about the characteristics of children with severe uncorrectable visual conditions is valuable for communicating with families, planning and implementing early intervention and educational programs, and collaborating with medical professionals.

Considerable progress has been made in preventing blindness in developed countries during the past century. However, a small percentage of young children continue to be diagnosed with uncorrectable visual impairments that may impede their optimal development and learning. Children with light perception or less visual ability are at a particular risk for developmental delay and adverse outcomes (Hatton, Bailey, Burchinal, & Ferrell, 1997). Consequently, these children need

immediate referral to early intervention and early childhood special education programs, so they can receive support from teachers with specialized expertise in the education of students who are blind. Indeed, Goal 1 of the National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities (Huebner, Wolffe, Merk-Adam, & Styker, 2004) affirms the need for early referral to intervention and education to facilitate optimal development and learning.

Private agencies in the United States have been providing specialized support for children with severe, uncorrectable visual impairments since the emergence of retrolental fibroplasia in the mid-20th century. Passage of the Education for All Handicapped Children Act amendments of 1986, P.L. 99-457, extended support to children with disabilities from birth to age 3, and federal funds were used to promote early referral to improve developmental and educational outcomes. Most infants and toddlers with severe visual impairments in the United States have had access to early intervention services since the late 1980s. Since the mid-1970s, most school-aged children with severe, uncorrectable visual impairments have been educated in their local schools with sighted peers with support from specialized teachers of students with visual impairments. These teachers serve a heterogeneous group of students—some may be totally blind and gifted, while others may have additional disabilities and relatively useful (20/70 to 20/200) vision. Regardless of their characteristics, families and educators agree that support during early childhood makes it more likely that children with visual impairments will succeed in their early formal education with sighted children and be "ready to learn" when they enter kindergarten.

Information about young children with severe visual impairments may allow vision care specialists to make earlier referrals. Information about the most prevalent visual conditions in these children has the potential to enhance clinical services and promote research to prevent or ameliorate severe, uncorrectable visual conditions. In addition, data can inform family support, early intervention and education, and the design of developmentally appropriate products to promote optimal outcomes (Hatton, Schwietz, Boyer, & Rychwalski, 2007).

In 1995, a number of agencies that provided specialized services to young children with visual impairments in the United States, along with researchers and medical professionals who were interested in child development and education of children with severe visual impairments, collaborated to establish a prospective registry of these children (Hatton, 2001). The overarching goal of the registry was to improve services for young children with severe, uncorrectable visual impairments and their families. In 2000, the American Printing House for the Blind (APH) assumed leadership through Babies Count (Hatton et al., 2007).

Representatives from these specialized agencies, researchers, and medical

professionals that were affiliated with the group agreed that data would be collected at the time that children were enrolled in specialized early intervention programs. The article presented here includes information on 5,931 young children with severe visual impairments in the United States, aged 3 and younger. Earlier data were reported on different cross-sectional samples of 406 (Hatton, 2001) and 2,155 (Hatton et al., 2007) children who were referred for early intervention because of severe visual impairments using the same instrument and data collection procedures.

The following questions provided the foundation for this article:

- What are the most prevalent visual conditions in young children with severe, uncorrectable visual conditions?
- What characteristics are commonly associated with the most prevalent visual conditions?
- What are the average ages at which young children with severe, uncorrectable visual conditions are diagnosed and referred for specialized services?
- How do the current findings compare to the data reported in 2007, and what differences are relevant for educators and medical professionals?

Method

Participants

From January 2005 through April 2011, data were collected on young children with visual impairments who were living in 28 states. These children, aged 39 months or younger, were referred for specialized services for children with visual impairments. To be eligible for services in most states, children must have a visual acuity of 20/70 or worse in the better eye after correction, a restricted visual field of 20 degrees or less, or a functional vision loss that impedes learning.

Table 1
Demographic characteristics of the children in the Babies Count Registry, 2005–11 (n = 5,931).

Characteristic	Number	Percentage
Gender		
Male	3,264	55
Female	2,602	44
Unknown	65	1
Ethnicity		
European American	3,361	57
Hispanic	1,315	22
African American	452	8
Other minority	730	12
Unknown	73	1
Mother's education		
Less than high school	790	13
High school graduate	1,404	24
Some college	1,599	26
Bachelor's degree	993	17
Graduate school	564	10
Unknown	581	10
Family		
Intact, two parents	4,650	78
Other	1,236	21
Unknown	45	1

Note: Percentages are rounded to the nearest whole number.

The primary caregivers of the 5,931 young children were interviewed about their children's visual abilities and diagnoses. The states that reported data for more than 500 children included Utah, California, Colorado, Arizona, and Massachusetts. An additional six states provided data for between 100 and 500 children. Ten states provided data for 10 to 99 children. See Table 1 for the demographic characteristics of the sample.

Procedure

The survey form that was used for the previous data collection was used for the present study (Hatton, 2001; Hatton et al., 2007). Professionals who were employed by the specialized early childhood programs that participated in the study invited the parents or caregivers of new referrals to participate in the Babies Count Registry. The registry and data collection form were designed for children aged 3 and younger. After the agencies obtained written consent to collect and share deidentified data with APH, data for the survey form were collected through interviews at the time of entry, reviews of records, and direct observations. The professionals who obtained consent and collected data were chosen and trained to administer the survey because of their expertise with young children with visual impairments.

A unique identifying code was used on the data collection forms instead of names. Completed forms were mailed to APH, where information was recorded electronically. Some agencies entered deidentified electronic data directly via an online secure server. These data were then transferred to the first author and converted to a STATA (StataCorp, 2009, Release 11-IC, College Station, Texas) data set. The Institutional Review Board at Vanderbilt University approved the analysis of the deidentified extant data. The first two authors screened the data before analyzing it and ran descriptive statistics. Chi-square analyses and *t*-tests were used to compare the results from the current study to selected findings from Hatton et al. (2007). As we noted earlier, data from 2007 were different from the current data set.

Findings

Prevalence of visual conditions

The three most prevalent visual conditions of the 5,931 young children who were referred to specialized agencies providing services for visual impairments were cortical visual impairment (CVI; 24.9%, $n = 1{,}480$), retinopathy of prematurity (ROP; 11.8%, $n = 700$), and optic nerve hypoplasia (ONH; 11.4%, $n = 674$). Children with structural disorders, such as anophthalmia, microphthalmia, and coloboma, made up 7.9% ($n = 468$) of the sample; retinal disorders, such as Leber's congenital amaurosis and rod-cone dystrophies, represented 5.5% ($n = 327$); and albinism accounted for 4.5% ($n = 264$) of the sample. Compared to Hatton et al.'s (2007) findings for a similar, but smaller, sample, the percentage of children with ROP decreased from 16.2% to 11.8% ($\chi^2_1 = 27.01$; $p < .001$), the percentage with structural disorders increased from 5.4% to 8.6% ($\chi^2_1 = 14.27$; $p < .001$), and the percentage with ONH increased slightly from 9.7% to 11.4% ($\chi^2_1 = 4.77$; $p = .029$). The prevalence of CVI did not change ($\chi^2_1 = 1.52$; $p = .218$).

Prevalence of additional disabilities

Data on the presence of additional disabilities were available for approximately 98.9% (5,865) of the sample. Among these participants, 34.7% ($n = 2{,}033$) were identified as having a single disability of visual impairment, while 28.3% ($n = 1{,}660$) were identified as having developmental delays, and 37.0% ($n = 2{,}172$) were identified as having disabilities other than developmental delays,

Table 2
Prevalence of additional disabilities by visual condition (n = 5,865).

Condition	Visual impairment only		Visual impairment and developmental delay		Visual impairment and additional disabilities	
	n	%	*n*	%	*n*	%
Cortical visual impairment, n = 1,480	216	15	429	29	835	56
Hatton et al. (2007), n = 509	*63*	*12*	*75*	*15*	*371*	*73*
Retinopathy of prematurity, n = 697	231	33	215	31	251	36
Hatton et al. (2007), n = 349	*153*	*44*	*127*	*36*	*69*	*20*
Optic nerve hypoplasia, n = 616	307	50	162	26	147	24
Hatton et al. (2007), n = 208	*109*	*52*	*43*	*21*	*56*	*27*
Structural,[a] n = 467	237	51	87	19	143	31
Hatton et al. (2007), n = 117	*51*	*44*	*7*	*6*	*59*	*50*
Retinal disorders,[b] n = 327	177	54	70	21	80	24
Hatton et al. (2007), n = 118	*34*	*29*	*12*	*10*	*72*	*61*
Albinism, n = 264	227	86	26	10	11	4
Hatton et al. (2007), n = 107	*93*	*87*	*9*	*8*	*5*	*5*
Other,[c] n = 1,501	495	33	501	33	505	34
Hatton et al. (2007)	*130*	*24*	*107*	*20*	*298*	*56*
Unknown, n = 513	143	28	170	33	200	39

[a] Structural = anophthalmia, microphthalmia, coloboma, and the like.
[b] Retinal disorders = Leber's congenital amaurosis, rod cone dystrophy, and so forth.
[c] Other = known visual conditions not included in the table.

such as cerebral palsy or deafness or hearing impairment. The percentage of children (34.7%) with only visual impairment was similar to the 32.2% ($\chi^2_1 = 4.25$; $p = .039$) identified in Hatton et al. (2007). Table 2 presents information on additional disabilities for specific visual conditions. Among the children with the three most prevalent visual conditions, 50% of those with ONH ($n = 307$) had only visual impairment compared to 33% ($n = 231$) of those with ROP ($\chi^2_1 = 37.69$; $p < .001$). Children with ROP were significantly more likely to have a single disability than children with CVI (15%; $n = 216$; $\chi^2_1 = 99.90$; $p < .001$). The percentage of children with ROP who had a single disability of visual impairment decreased significantly from 43.8% ($n = 153$) in Hatton et al. (2007) to 33.1% ($n = 231$) in the current sample ($\chi^2_1 = 11.45$; $p < .001$), although the percentage of children with retinal disorders and only visual impairment increased significantly from 28.8% ($n = 34$) to 54.1% ($n = 177$; $\chi^2_1 = 22.29$; $p < .001$). Changes in the prevalence of additional disabilities in other visual conditions were not significant.

Functional vision

Legal blindness status was known for approximately 29.3% ($n = 1,739$) of the total sample, with 60.2% ($n = 1,047$) identified as legally blind. This latter percentage was similar to the 62.6% of 1,378 children whose functional vision status was known in 2007 who were identified as legally blind ($n = 862$). Table 3 presents information about

Table 3
Visual awareness and object perception.

Condition	Awareness of		Following	
	Lights	Objects	Lights	Objects
Cortical visual impairment (*n* = 654)	93% (*n* = 611)	80% (*n* = 521)	57% (*n* = 375)	52% (*n* = 338)
Retinopathy of prematurity (*n* = 371)	92% (*n* = 340)	82% (*n* = 305)	70% (*n* = 261)	67% (*n* = 250)
Optic nerve hypoplasia (*n* = 285)	83% (*n* = 236)	62% (*n* = 178)	52% (*n* = 147)	45% (*n* = 128)
Structural[a] (*n* = 229)	90% (*n* = 205)	76% (*n* = 174)	67% (*n* = 153)	64% (*n* = 146)
Retinal disorders[b] (*n* = 164)	91% (*n* = 150)	82% (*n* = 135)	71% (*n* = 117)	63% (*n* = 104)
Albinism (*n* = 148)	100% (*n* = 148)	96% (*n* = 142)	93% (*n* = 137)	89% (*n* = 132)
Other[c] (n = 731)	97% (*n* = 712)	90% (*n* = 661)	80% (*n* = 586)	75% (*n* = 548)

[a] Structural = anophthalmia, microphthalmia, coloboma, and the like.
[b] Retinal disorders = Leber's congenital amaurosis, rod cone dystrophy, and so forth.
[c] Other = known visual conditions not included in the table.
Note: Data on children whose visual conditions were unknown were not included in this table.

visual awareness and object perception by visual condition.

Ages of children at their diagnosis, referral, and entry into specialized programs

The ages of the 5,931 children in the study ranged from birth to 38.6 months. Data on the age of diagnosis, referral, and entry into specialized programs were reported for 93.4% (*n* = 5,537) of the sample. The mean age at which the children received a visual diagnosis was 4.9 months (*SD* = 5.7). On average, referrals for specialized services for young children with visual impairments were made at 10.5 months (*SD* = 7.8). Entry into specialized programs occurred approximately one month later, at 11.6 months (*SD* = 8.0). The age at the time of diagnosis was significantly younger ($t = 3.95$; $p < .001$; 95% CI .30–.90) than the age at the time of diagnosis for infants reported by Hatton et al. in 2007. However, the age at the time of referral ($t = 2.62$; $p < .01$; 95% CI .13–.87) and entry ($t = 2.57$; $p = .01$; 95% CI .12–.88) into programs was later. See Table 4 for the ages of diagnosis, referral, and entry for specific visual conditions.

The three most prevalent visual conditions tended to be diagnosed at slightly earlier ages than was reported in Hatton (2007). Specifically, CVI was diagnosed at a mean age of 6.8 months (*SD* = 6.1) compared to 7.6 months (*SD* = 6.0) in 2007 ($t = 2.43$; $p = .015$; 95% CI .15 − 1.45). ROP was diagnosed at a mean age of 2.8 months (*SD* = 4.3) compared to 3.4 months (*SD* = 3.3) in 2007 ($t = 2.28$; $p = .023$; 95% CI .08 − 1.12). ONH was diagnosed at a mean age of 4.2 months (*SD* = 4.5) compared to 5.0 months (*SD* = 4.8) in 2007 ($t = 2.05$; $p = .041$; 95% CI .03 − 1.57).

In the current sample, the children with ROP were diagnosed earlier, at a mean age of 2.8 months (*SD* = 4.3), than were the children with ONH, who were diagnosed at an average age of 4.2 months (*SD* = 4.5; $t = 5.79$; $p < .001$; 95% CI .93 – 1.87), and the children with CVI, who were diagnosed at a mean age of 6.8 months (*SD* = 6.1; $t = 17.3$; $p < .001$; 95% CI 3.55 – 4.45). However, the children with ROP were referred at 10.1

Table 4
Mean age in months (standard deviations in parentheses) of critical events by visual condition (n = 5,537).

Condition	Diagnosis of visual impairment	Referral to a specialized program	Entry into a specialized program
Cortical visual impairment, n = 1416, 26%	6.8 (6.1)	11.1 (7.6)	12.2 (7.8)
Hatton et al. (2007)	7.6 (6.0)	11.5 (7.6)	12.6 (7.8)
Retinopathy of prematurity, n = 674, 12%	2.8 (4.3)	10.1 (6.9)	11.3 (7.0)
Hatton et al. (2007)	3.4 (3.3)	9.6 (6.7)	10.9 (6.9)
Optic nerve hypoplasia, n = 654, 12%	4.2 (4.5)	8.2 (6.6)	9.4 (7.0)
Hatton et al. (2007)	5.0 (4.8)	8.4 (7.0)	9.8 (7.2)
Structural,[a] n = 459, 8%	2.2 (4.4)	6.9 (7.3)	8.1 (7.6)
Hatton et al. (2007)	1.5 (2.9)	6.1 (6.7)	7.0 (6.8)
Retinal disorders,[b] n = 321, 6%	4.8 (5.1)	10.7 (8.0)	11.6 (7.9)
Hatton et al. (2007)	5.5 (4.9)	9.5 (6.7)	10.6 (6.8)
Albinism, n = 256, 5%	3.3 (4.3)	9.4 (7.9)	10.5 (8.1)
Hatton et al. (2007)	4.0 (2.8)	8.0 (6.4)	9.0 (6.8)
Other,[c] n = 1,399, 25%	5.3 (6.0)	12.1 (8.4)	13.1 (8.4)
Hatton et al. (2007)	6.1 (6.1)	10.5 (7.8)	11.6 (7.8)
Unknown, n = 358, 6%	5.2 (6.3)	11.4 (8.3)	12.3 (8.3)

[a] Structural = anophthalmia, microphthalmia, coloboma, and so forth.
[b] Retinal disorders = Leber's congenital amaurosis, rod cone dystrophy, retinoblastoma, and the like.
[c] Other = known visual conditions not included in the table.

months (SD = 6.9), later than the children with ONH, who were referred at 8.2 months (SD = 6.6; t = 5.13; $p < .001$; 95% CI 1.17 – 2.63). The children with ROP also entered programs later, at a mean age of 11.3 months (SD = 7.0), than did the children with ONH, who entered at 9.4 months (SD = 7.0; t =4.95; $p < .001$; 95% CI 1.15 – 2.65). The children with CVI were older than the children with ROP at the time of referral, with an average age of 11.1 months (SD = 7.6 months; t =3.00; $p < .01$; 95% CI .35 – 1.65) and entry, with an average age of 12.2 months (SD = 7.8; t =2.65; $p < .01$; 95% CI .23 – 1.57). Of the 3,228 children for whom referral source data were available, 44.8% (n = 1,445) were referred by generic early intervention providers (that is, those without specialized expertise in visual disabilities), while 37.6% (n = 1,214) were referred by medical professionals.

Discussion

On the basis of reviews of both the medical and social sciences literature, we have presented data on the largest sample of young children with severe, uncorrectable visual impairments reported to date. Information about these children is of value to both educators and medical professionals for service delivery and the prevention of these disorders. It also highlights the need for collaboration among teachers of children with visual impairments, early interventionists, and medical professionals (and their support staff members).

Most prevalent visual conditions

CVI, ROP, and ONH continue to be the most prevalent diagnoses in children with

severe, uncorrectable visual impairments, consistent with earlier reports (Hatton, 2001; Hatton et al., 1997; Hatton et al., 2007; Kong, Fry, Al-Samarraie, Gilbert, & Steinkuller, 2012; Steinkuller et al., 1999). The percentage of children with CVI appears to have remained relatively stable since 2001 (varying only from 21.2% to 23.6% to 24.9%) (Hatton, 2001; Hatton et al., 2007). Although the percentage with ROP decreased from 17.0% in 2001 to 16.2% in 2007 to 11.8% currently, the percentage of children with ONH increased from 7.6% in 2001 to 9.7% in 2007 to 11.4% currently (Hatton, 2001; Hatton et al., 2007).

Although ROP is responsible for about 13% of childhood blindness in the United States and appears to be decreasing, it is increasingly being diagnosed in developing countries (Gilbert et al., 2005; Kong et al., 2012). Continuing advances in medical technology have resulted in improved outcomes for extremely premature infants. These advances do not mean, however, that ROP will be eradicated in the United States, particularly in rural areas that may lack access to the latest medical technology. Laser therapy is currently the primary treatment for ROP, and a number of clinical trials are under way to target genetic and molecular mediators that may be more viable options for treatment in rural areas (Mataftsi, Dimitrakos, & Adams, 2011; Rivera et al., 2011).

In our sample, the prevalence of ONH appears to have increased slightly, consistent with other reports (Garcia-Filion et al., 2008). Greater awareness of ONH may have accounted for both the earlier diagnosis of ONH and earlier recognition of additional disabilities. In a study of 204 children with ONH who were aged 36 months or younger, young maternal age (mothers aged 22 and younger) and primaparity (first pregnancy) were associated with ONH, as were low maternal weight gain, weight loss during pregnancy, preterm labor, and gestational vaginal bleeding (Garcia-Filion et al., 2008). Weight loss during pregnancy and maternal age may be amenable to intervention and deserve further study to elucidate their association with ONH.

Multiple disability risk status

The percentage of children we studied with developmental delays and additional disabilities, 65.3%, appears to have remained stable (67.8% in 2007; Hatton, unpublished data) from 2007 (Hatton et al., 2007) to the present. However, the percentage of children with ROP and additional diagnoses increased significantly ($p < .001$). Children with ROP typically are among the sickest, youngest, and smallest infants to survive prematurity. The data for ROP may reflect the increased availability of life-sustaining medical interventions; more children with ROP may survive, but they may be more likely to have additional disabilities. Co-occurring disabilities appear to be increasing in children with ROP at the same time that the percentage of children with ROP is decreasing. This finding seems consistent with the medical literature that has suggested that gestationally young premature infants with severe visual impairments may have poorer outcomes. (Mataftsi, Dimitrakos, & Adams, 2011; Rivera et al., 2011).

The percentage of children with ONH and multiple disabilities remained relatively stable, from 38.7% in 2001 (Hatton, 2001) to 47.6% in 2007 (Hatton et al.,

2007) to 50.2% currently ($p = .213$). This finding is not consistent with that of Garcia-Filion et al. (2008), who reported that 78% of a sample of 73 children with bilateral ONH who were studied prospectively at age 36 months and again at 5 years had developmental delays at age 5. The discrepancy may be due to the younger age of the children in the current study; the signs of developmental delays may have been too subtle to detect during infancy and toddlerhood. Garcia-Filion, Fink, Geffner, and Borchert's (2010) prospective research documented that only 10% of their sample had no neuroradiographic or endocrine abnormalities. Only 4 of the 6 children among the 10% did not have developmental delays. Hypothyroidism was strongly associated with developmental delays, as was hypoplasia of the corpus callosum. Other endocrinopathies associated with ONH and developmental delays were growth hormone deficiency, adrenocorticotropic hormone deficiency, and diabetes insipidus (Borchert, 2012; Garcia-Filion et al., 2008). These findings document the need for referrals to endocrine workups for all children with ONH; perhaps medications and supplements can ameliorate the developmental delays associated with ONH. Brodsky, Conte, Taylor, Hoyt, and Mrak (1997) reported five cases of sudden death in young children with ONH and endocrine abnormalities, making the issue of referral for hormonal abnormalities even more critical.

Similarly, the percentage of children with albinism and developmental delays or other disabilities remained stable over time, with only 14% of the current sample being described as having a developmental delay or co-occurring disability. In a sample of 78 children with albinism, Kutzbach, Summers, Holleschau, King, and MacDonald (2007) reported that 3 (4%) had a diagnosis of pervasive developmental disorder (PDD) and 17 (22%) had a diagnosis of attention deficit hyperactivity disorder (ADHD). Again, though, the mean age of the 78 children in that sample was 9.14 years, much older than the current sample. Because children in the current sample were so young, symptoms of ADHD and PDD may not yet have been evident. Knowing that children with albinism may develop PDD and ADHD at later ages may be helpful for educators and families because these disorders, rather than low vision, may contribute to problems in school.

Early intervention, education, and medical services for children with a single disability of visual impairment are often quite different from those for children with multiple disabilities, who tend to have poorer outcomes. Increases in multiple disabilities in children with severe visual impairments can affect the allocation of resources, professional development needs, and university programs that prepare medical and allied health professionals and teachers. Therefore, the increase in multiple disability risk status in infants and toddlers with ROP is of concern and should be the topic of further research. Perhaps some of the new treatments directed at genetic and molecular targets will prove useful in reducing the impact of extreme prematurity (Gilbert et al., 2005).

Functional vision

In the United States, children who are identified as being legally blind are entitled to resources that promote early development through APH; therefore, the

documentation of legal blindness is particularly important, even for children at young ages. However, for at least 40% of the samples reported since 2001 (Hatton, 2001; Hatton et al., 2007), legal blindness status was reported as unknown. If possible, it would be helpful for medical professionals to consider using preferential visual acuity assessments with these young children to assess whether they are legally blind; perhaps support staff members can learn to perform these preferential looking assessments.

Ages of critical events

Visual conditions were diagnosed on average at 4.9 months, consistent with data reported in Hatton (2001), but earlier than the average age of 5.5 months reported by Hatton et al. in 2007. The findings suggest that there may not be much margin for lowering the age of diagnosis of the most severe visual impairments in young children. The increased attention to early intervention for children with disabilities and the easily recognized symptoms of severe conditions may account for the earlier diagnoses. Of course, children with ROP would be identified before they are discharged from the hospital following birth, as would some children with structural defects. The age for a CVI diagnosis was about a month earlier than in previous reports, suggesting that ophthalmologists are more attuned to this disorder. It is interesting that the age at which ONH has been diagnosed has been steadily decreasing from 8.6 months in 2001 (Hatton, 2001) to 5.0 months in 2007 (Hatton et al., 2007) to 4.2 months currently. Research by Borchert (2012) and his colleagues (Garcia-Filion et al., 2008; Garcia-Filion et al., 2010; Ma, Fink, Geffner, & Borchert, 2010) on ONH may have contributed to increased awareness.

Overall, children were diagnosed on average two weeks earlier than in 2007 (4.9 months rather than 5.5 months); however, they were referred to early intervention and entered early intervention programs two weeks later than in 2007 (Hatton et al., 2007). Parents of very young children with severe, uncorrectable visual impairments may be depressed and immobilized by the prospect of having a child with a severe disability (Hatton, McWilliam, & Winton, 2002, 2003). Many have never had experiences with successful adults who are blind and do not realize that their children can attend neighborhood schools with their sighted peers. Medical professionals may consider asking parents for permission to refer their young patients to early intervention directly to reduce this lag. Perhaps medical support staff members can establish relationships with early intervention agencies and serve as liaisons to families who may be too overwhelmed to contact early intervention agencies directly.

Specialized agencies that provide services for infants and toddlers with visual impairments should establish collaborative relationships with local ophthalmologists, optometrists, and pediatricians to facilitate earlier referrals. Early interventionists and parents constantly observe children's use of vision and other senses; therefore, they can provide medical professionals with detailed information about young children's use of vision. Children are often frightened in clinical settings, and medical professionals have limited time to establish rapport and complete examinations. Because most children

with severe visual impairments in the United States are educated in local schools with sighted children, early intervention to promote optimal development and learning is critical. Earlier referral to specialized services for infants and toddlers with visual impairments and ongoing collaboration among ophthalmologists, families, and members of early intervention teams (including educators, therapists, and social workers) can help these children achieve their potential and help families cope.

Limitations

Even though data on severe, uncorrectable visual impairments are rare (Gilbert et al., 2005; Kong et al., 2012) and the sample reported in this article is the largest reported to date, we must acknowledge a number of limitations. First, data for some children were incomplete. Although the data collectors used a consistent protocol and were trained to collect data at their agencies, more controlled procedures for collecting and verifying data would have been ideal. The agencies did not collect data on the number of families who declined to participate, and so there is no way to determine the response rate or if children whose families declined to participate differed from those for whom data were available. A prospective multisite study of infants and toddlers with visual impairments with more rigorous data-collection procedures could provide more definitive information about these children. Realistically, though, the resources to conduct such a study are not readily available. It is remarkable that agencies that are scattered across the United States, often with limited resources, have collaborated for the past 17 years to collect and report data on infants and toddlers with severe, uncorrectable visual impairments.

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