

Vision Impairment in Australian Children

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Abstract

The Child and Family Services (CAF) Section of the Royal Blind Society (RBS) provides services for children and adolescents with a vision impairment throughout NSW and the ACT. Between January 1990 and December 1998, 1768 new referrals were received for clients aged between 9 days and 19.2 years.

This study was designed to determine the major causes of vision impairment, and subsequent referral to CAF, during this 9 year period. Results show that there is often more than one cause for impaired vision, with 120 primary and 35 secondary conditions being identified. The primary diagnoses have also been grouped according to the World Health Organisation (WHO) classifications for children with blindness and low vision.

Other areas addressed in this study, with relationship to the primary ocular diagnosis, include gender, age at referral, length of required RBS intervention, last recorded level of vision, and the most common secondary ocular associations. Additionally, the orthoptist's role with children who have a vision impairment is discussed.

Keywords: Vision impairment, children, Royal Blind Society, primary condition, secondary association, length of service, referral age, visual acuity, orthoptist, orthoptic assessment.

Introduction

Visual impairment is the consequence of a functional loss of vision, rather than the eye disorder itself (1). In 1995, the World Health Organisation (WHO) estimated that, globally, 1.5 million children were blind, a total of 5 million children were visually disabled and that 3.8% of blind people were aged between 0 and 14 years (2). In 1993, the Australian Bureau of Statistics (ABS) estimated that 0.4% of all Australian children aged less than 15 years were blind or vision impaired (3). In the USA, visual impairment occurs in 1% of individuals under the age of 18 years (4).

The causes of vision impairment vary from place to place, between more developed and less developed countries, urban versus remote areas. World-wide, 90% of children who are blind live in developing countries (5), with 80% of blindness reported to be avoidable, preventable or curable (2) (6). Mortality rates are often high in conditions that have secondary blindness (7). In third world countries, preventable causes of blindness predominate (for example cataract, Vitamin A deficiency and trachoma) whereas in

developed countries, non-preventable causes, such as retinopathy of prematurity (ROP), cortical vision impairment (CVI) and optic nerve hypoplasia prevail (7).

In Australia, there is no centralised national or state register for blindness or partial sight (8). Data can only be compared to previous findings within agencies recognised for the rehabilitation of people who are blind or vision impaired, such as the Royal Blind Society (RBS) in New South Wales. The Child and Family Services (CAF) section of RBS provides assistance to children, from birth to approximately 18 years of age and their families, throughout NSW and the ACT. Early childhood intervention and school-aged services are offered via a team of orthoptists, physiotherapists, occupational therapists, psychologists, social workers and early childhood special education teachers. From computer database statistics, the average number of new referrals in the 1980s to CAF each year was 137, with this figure increasing to 196 per year in the 1990s.

In order to determine current causes of vision impairment amongst a paediatric Australian population, data was collected from RBS. The current study identifies the ocular reasons for referral to CAF between January 1990 and December 1998, for children and adolescents aged between 9 days and 19.2 years. Additionally, the role of the orthoptist with children who are vision impaired is discussed.

Method

Details of 1768 new CAF referrals over the specified 9-year period were obtained from the computer database. It should be acknowledged that RBS service provision for each child was not continuous over the entire 9 years, but rather was received at intermittent periods. The length of service provision was noted as well as the primary ocular diagnosis and level of visual acuity at the time of discharge. Associated, or secondary, ocular conditions were also recorded. The difference between the child's age and the time of initial referral was evaluated in order to determine whether certain conditions were referred at an earlier age than others. If the gender of the child was not on the database, it was inferred, where possible, by the child's first name. At the time of discharge from RBS services, confirmation was given as to whether the original ocular condition at referral was the true cause of the child's vision impairment. Not all clients could be included in each area of data analysis due to missing information, for example, no date of birth or primary ocular diagnosis.

For inclusion in this study, the minimum age of nine days was selected as this was considered to be the youngest feasible age for referral of a child.

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Additionally, it was felt that any ages listed as younger may have been computer database errors. The uppermost age relevant for adolescent services was 19.2 years as, at RBS, young people are transferred to the adult service area upon leaving school. Beyond these age limits, there was a decline in the number of cases.

When more than one ocular condition had been cited as a cause of vision impairment, they were ordered into 'primary' and 'secondary', for example, in one case of optic atrophy and cortical vision impairment, optic atrophy was considered to be the primary cause of the vision impairment. Some children had non-specific causes of vision loss recorded, such as eye muscle problem or tracking problems - in these cases, no primary diagnosis was recorded. Additionally, some conditions entered on the database were quite specific, for example, corneal dystrophy, corneal disease, corneal transplant. If listed in this way, each was counted as a separate diagnosis, rather than under the heading 'cornea', leading to a large number of overall diagnoses being cited. The recorded frequency of other conditions, such as myopia, may be a misrepresentation of their true frequency, as they are often part of a general syndrome, such as myopia with Marfan's Syndrome.

In total, 120 primary and 35 secondary singular conditions were identified. Each of these was coded, with the primary conditions also grouped under headings employed by WHO in its Programme for the Prevention of Blindness (PBL) (9) (Table 1). Only the ten most frequently occurring causes of visual impairment (referred to as 'Ungrouped') were analysed in this current study, due to the large number of primary conditions. The ten most common areas identified using the WHO/PBL classifications will be referred to as 'WHO Groups'.

Visual acuity results were graded according to those limits used by WHO/PBL (9) (Table 2). This study used the best recorded level of vision as its measurement, for example, if one eye was 6/6 and the other eye blind, 6/6 was recorded. In cases such as these, the child still has functional vision, despite the apparent 'vision impairment'.

Table 1: WHO (PBL) Classifications.

Classifications Employed by World Health Organisation (WHO) in its Programme for the Prevention of Blindness (PBL).

Whole Globe (phthisis, anophthalmos, microphthalmos, buphthalmos, glaucoma, removed, disorganised, other);
Cornea; Lens; Uvea; Retina; Optic Nerve;
Globe appears normal (refractive error, cortical blindness, nystagmus, amblyopia);
Other (trauma, ocular muscle involvement, field loss, squint, syndrome and tumour).

Table 2: WHO Visual Acuity Categories.

WHO Visual Acuity Categories

1 = 6/6 - 6/18 2 = <6/18 - 6/60 3 = <6/60 - 3/60
4 = <3/60 - PL 5 = no light perception

Results and Discussion

Primary Conditions and Number of Cases

Results show that the most common 'Ungrouped' conditions accounted for over half (966 children) of the referrals received during the 9-year period (Table 3). The most commonly referred cause of vision impairment was CVI (9.4%), followed by cataract.

Table 3: Ten Most Common Primary Conditions Identified.

UNGROUPED		
PRIMARY OCULAR CONDITION	NO. OF CASES	% OF ALL CASES
Cortical Vision Impairment (CVI)	159	9.4
Cataract	155	9.2
Nystagmus	129	7.6
Optic Atrophy	120	7.1
Myopia	98	5.8
Ocular Albinism	71	4.2
Retinopathy of Prematurity (ROP)	70	4.1
Hypermetropia	61	3.6
Oculocutaneous Albinism	54	3.2
Retinitis Pigmentosa	49	2.9
TOTAL	966	57.1

Under WHO classification (Table 4), retinal problems were the main reason for referral, accounting for almost two and a half times more children than that of CVI in the non-grouped categories (Table 3). This contrast in figures is due to 29 conditions coming under the heading of 'retina'.

Globally, trachoma is still the main global cause of preventable blindness amongst all ages. It is estimated that 146 million people have this active disease, with 10 million having trichiasis and 6 million being blind (2). Vitamin A deficiency is considered to be the leading cause of childhood blindness (1995) (4). Neither trachoma nor Vitamin A deficiency were identified causes for referral from the database.

Table 4: Primary Conditions as per WHO Grouping.

WHO GROUPS		
PRIMARY OCULAR CONDITION	NO. OF CASES	% OF ALL CASES
Retina	365	21.6
Optic Nerve	176	10.4
Refractive Error	156	9.2
Lens	150	8.9
Cortical Blindness	133	7.9
Nystagmus	119	7.0
Uvea	59	3.5
Whole Globe	39	2.3
Syndrome	38	2.2
Cornea	32	1.9
TOTAL	1267	74.9

It has been observed, world-wide, that CVI is becoming more prevalent (1994) (4). By comparing this current study to another performed at RBS for the period 1980-1989 (10) (Table 5), it can be seen that there has been a slight decrease in the number of

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children referred with CVI. In the developed world, congenital cataract, when appropriately managed, is the only cause of visual defect to have recently (1994) shown a decrease in prevalence (4), which is also reflected in Table 5. A USA study in 1980 estimated that prenatal cataract was the leading cause of legal blindness among children under 5 years of age (4). A further study in 1996 found the most common cause of vision impairment in children aged 0-5 years to be ROP (4).

Table 5: Comparison of Referral Conditions Between 1980-1989 RBS Study and 1990-1998 RBS Study.

1980 - 1989	1990 - 1998
CVI 12.3%	CVI 9.4%
Cataract (not Rubella) 12.0%	Cataract 9.2%
Optic Atrophy 10.3%	Nystagmus 7.6%
Albinism 7.0%	Optic Atrophy 7.1%
ROP 6.0%	Myopia 5.8%
Congenital Nystagmus 3.6%	Ocular Albinism 4.2%
Glaucoma 3.0%	ROP 4.1%
Coloboma 3.0%	Hypermetropia 3.6%
Microphthalmia 3.0%	Oculocutaneous Albinism 3.2%
Optic Nerve Hypoplasia 2.7%	Retinitis Pigmentosa 2.9%

Verification of Primary Diagnosis

Of the 1692 cases in this study with a primary cause identified, 72.8% had had the ocular condition verified by the time of discharge. The most readily confirmed condition was Ocular Albinism (87.1%), followed by Oculocutaneous Albinism (85.2%) and ROP (80%). 'Hypermetropia', as a primary diagnosis, was the least verified condition. Although it is one of the main reasons for referral, CVI appears to be one of the more difficult conditions to confirm (68.6%).

Primary Conditions and Gender

Results showed that 58.6% of clients were male and 41.4% were female. These proportions are also reflected in the number of Australian people with a primary vision impairment who receive disability support from the government, whereby 58% are male and 42% female (1997) (11).

With regard to the Ungrouped conditions, the number of males outweighed that of females in each condition, except for ROP (Table 6).

Table 6: Distribution of Gender in the Ungrouped Primary Conditions.

PRIMARY CONDITION	MALE (%)	FEMALE (%)
CVI	64.8	35.2
Cataract	51.6	48.4
Nystagmus	66.4	33.6
Optic Atrophy	60.2	39.8
Myopia	64.3	35.7
Ocular Albinism	60.6	39.4
ROP	48.6	51.4
Hypermetropia	57.4	42.6
Oculocutaneous Albinism	70.4	29.6
Retinitis Pigmentosa	53.1	46.9

Length of Service

Those clients still receiving the services of RBS at the conclusion of this study were not included in the summary. As shown in Table 7, those children with ROP as their primary diagnosis required the longest average period of service, that is, 2 years per child. This condition also demonstrated the broadest variation in the amount of RBS service provision for each individual, ranging from 0.7 months to 95.7 months duration. When the length of service was considered using the grouped WHO headings (Table 8) conditions affecting the whole globe required the greatest average length of service per child (1.8 years). Retinal problems displayed the greatest range of required intervention, with one child needing only two weeks through to another who was a client of RBS for 8.3 years. The short duration of RBS intervention for some of these conditions may be due to the child receiving services from other sources or agencies.

Table 7: Length of Service for Ungrouped Primary Conditions.

PRIMARY CONDITION	UNGROUPED	
	RANGE OF LENGTH OF SERVICE (MONTHS)	AVERAGE LENGTH OF SERVICE (MONTHS)
ROP	0.7 - 95.7 (7.9 years)	23.6 (2.0 years)
Oculocutaneous Albinism	0.9 - 87.2 (7.2 years)	21.8 (1.8 years)
Ocular Albinism	0.5 - 66.4 (5.5 years)	17.3 (1.4 years)
Optic Atrophy	1.0 - 68.0 (5.6 years)	14.6 (1.2 years)
CVI	1.0 - 45.4 (3.7 years)	14.2 (1.2 years)
Cataract	0.1 - 89.2 (7.4 years)	11.9 (1.0 years)
Retinitis Pigmentosa	1.3 - 37.4 (3.0 years)	11.2 (0.9 years)
Nystagmus	0.7 - 65.1 (5.4 years)	9.4 (0.8 years)
Myopia	0.4 - 37.8 (3.1 years)	6.1 (0.5 years)
Hypermetropia	0.2 - 27.8 (2.3 years)	4.7 (0.4 years)

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Table 8: Length of Service for WHO Grouped Conditions.

PRIMARY CONDITION	WHO GROUPS	
	RANGE OF LENGTH OF SERVICE (MONTHS)	AVERAGE LENGTH OF SERVICE (MONTHS)
Whole Globe	0.2 - 80.6 (6.7 years)	21.1 (1.8 years)
Uvea	0.5 - 70.2 (5.8 years)	20.9 (1.7 years)
Retina	0.5 - 100.1 (8.3 years)	17.9 (1.5 years)
Optic Nerve	0.1 - 68.0 (5.7 years)	14.8 (1.2 years)
Cortical Blindness	1.0 - 45.4 (3.7 years)	14.2 (1.2 years)
Syndrome	1.5 - 90.0 (7.4 years)	12.9 (1.1 years)
Lens	0.7 - 89.2 (7.4 years)	12.1 (1.0 years)
Nystagmus	0.7 - 65.1 (5.4 years)	9.4 (0.8 years)
Cornea	1.1 - 18.2 (1.4 years)	6.1 (0.5 years)
Refractive Error	0.2 - 37.8 (3.1 years)	5.4 (0.5 years)

Age at Referral

CVI and ROP were both referred within a comparable age span (2 months to 200 months), with the same average age at referral (3 years). Retinitis Pigmentosa showed to be referred at a much later age, which reflects the nature of this particular condition (Table 9).

Table 9: Range of Age and Average Age at Referral for Ungrouped Primary Conditions.

PRIMARY CONDITION	RANGE OF AGE AT REFERRAL (MONTHS)	AVERAGE AGE AT REFERRAL (MONTHS)
CVI	2 - 202	35.7 (3.0 years)
ROP	2 - 197	36.8 (3.1 years)
Oculocutaneous Albinism	9 days - 177	49.9 (4.2 years)
Cataract	16 days - 208	58.7 (4.9 years)
Ocular Albinism	2 - 213	62.3 (5.2 years)
Nystagmus	3 - 190	79.7 (6.6 years)
Hypermetropia	10 - 188	79.9 (6.7 years)
Optic Atrophy	3 - 214	83.6 (7.0 years)
Myopia	4 - 216	103.1 (8.6 years)
Retinitis Pigmentosa	25 - 216	118.6 (9.9 years)

Secondary Conditions and Their Association with Primary Conditions

Squint was the most common secondary association identified, followed by nystagmus (Table 10). When analysing these results further, there appears to be co-morbidity of some primary and secondary disorders. Myopia and cataract had the greatest number of secondary associations and oculocutaneous albinism the least number. Myopia was often noted with astigmatism and nystagmus, whilst cataract was most linked with glaucoma. In other studies, it has been reported that CVI often exists with ROP (12). It has also been documented that CVI, ROP and optic nerve hypoplasia have high rates of associated systemic multiple impairments (7). In the present study, CVI was most often associated with optic atrophy.

Table 10: Most Common Secondary Ocular Conditions.

SECONDARY CONDITION	NUMBER OF REPORTED CASES
Squint	61
Nystagmus	59
Astigmatism	48
Myopia	37
CVI	29
Microphthalmos/Microcornea	21
Hypermetropia	20
Glaucoma	19
Cataract	19
Amblyopia	15
Field Loss	14
Blind Other Eye	11

Levels of visual acuity

Visual acuity was analysed in two ways. First, by a recorded result, however, it can be difficult to gain a measurement in some conditions, such as CVI, and often only a subjective summation can be gained from clinical observation. Second, the range of vision for each condition was obtained.

i) Recorded Visual Acuity

At the time of discharge, 66.6% of cases had a recorded level of vision. Of those Ungrouped conditions, CVI was the only one in which the majority of children were not able to have a recorded measurement. Myopia was the condition for which most children had a recorded visual acuity, followed by nystagmus. Under WHO classifications, nystagmus was more likely to have a visual acuity obtained. A high percentage of those children with a problem of the 'Whole Globe' also showed a measurable level of vision. This high proportion may be explained if the ocular problem only pertained to one eye, allowing the best level of vision from the 'sound eye' to be noted.

ii) Range of Vision

CVI was the condition with the most evenly widespread levels of vision. The majority of Ungrouped conditions had levels of vision ranging between the bands of '6/6-6/18' to 'Light Perception'

(Table 11). Over half (57%) of those children with a cataract had vision ranging from '<6/18-6/60', however, 94% had a visual acuity that was 6/60 or better. Only 49.2% of children with CVI had 6/60 or better, with the majority (36.9%) having vision of '<3/60- Light Perception'. All cases with retinitis pigmentosa had vision of 6/60 or better (Table 11). Within the WHO Groups, visual acuity, in the majority of conditions, extended to No Light Perception.

The visual acuities found in children with CVI cover a broad spectrum of levels. This is supported by Crossman (13) who categorised vision in CVI as "sees beyond 1 metre with visual-perception problems remaining" to "no apparent vision". Crossman also stated that "vision tends to fluctuate, being influenced by such factors as fatigue, a noisy or unfamiliar environment, medication, illness and seizures. Fluctuations can be from hour to hour or day to day". Additionally, "peripheral vision appears to be more functional than central". Taylor and Hoyt (14) suggest that a form of 'blindsight', "a preservation of visual functioning in a defective visual field", may be responsible for the relatively good navigational skills of a child with severe cerebral blindness.

Table 11: Range of Visual Acuity in Ungrouped Conditions.

UNGROUPED		
PRIMARY CONDITION	VISION OF MAJORITY	RANGE OF VISION
Cataract	94%: 6/60 or better Maj.:57%: <6/18-6/60	6/6-6/18 - No LP
CVI	49.2%: 6/60 or better Maj.:36.9%: <3/60-LP	6/6-6/18 - No LP
Nystagmus	94.5%: 6/60 or better Maj.:59.6%: <6/18-6/60	6/6-6/18 - <3/60-LP
Optic Atrophy	73.5%: 6/60 or better Maj.:51.8%: <6/18-6/60	6/6-6/18 - No LP
Myopia	92.9%: 6/60 or better Maj.:60%: <6/18-6/60	6/6-6/18 - <3/60-LP
Hypermetropia	97.6%: 6/60 or better Maj.:73.8%: 6/6-6/18	6/6-6/18 - <6/60-3/60
ROP	68%: 6/60 or better Maj.:54%: <6/18-6/60	6/6-6/18 - No LP
Ocular Albinism	89.5%: 6/60 or better Maj.:62.5%: <6/18-6/60	6/6-6/18 - <6/60-3/60
Oculocutaneous Albinism	75%: 6/60 or better Maj.:71.9%: <6/18-6/60	6/6-6/18 - <3/60-LP
Retinitis Pigmentosa	100%: 6/60 or better Maj.:66.7%: 6/6-6/18	6/6-6/18 - <6/18-6/60

The effect of a cataract on visual acuity is dependant on the extent of maturity and location of the

opacity, whilst the level of vision when the optic nerve is involved is related to the number of neurones or nerve fibres affected. Residual vision in ROP parallels the grade of ROP reached - vision may be 6/6 or No Light Perception if total retinal detachment has occurred. Albinism is accompanied by reduced vision due to defective fundus pigmentation, foveal hypoplasia, nystagmus and possible refractive error. In the study, all children with retinitis pigmentosa had vision of at least 6/60, reflecting the age of the subjects and the general preservation of central vision until late in the progress of the disease.

The Role of the Orthoptist

An orthoptist is skilled in the visual assessment of a paediatric population. For an orthoptist to gain maximum results, it is essential that he/she has a vast knowledge of causes of vision impairment. Understanding the details of ocular conditions such as albinism or retinitis pigmentosa, will give the orthoptist an idea of visual expectations for the child, and the conditions under which each test should be performed. The orthoptist needs to acknowledge the child as a whole and their overall functioning abilities, not just their ocular diagnosis. Often, the children seen in CAF have multiple disabilities, particularly if they have CVI. It has been documented that children with intellectual and multiple disabilities exhibit an incidence rate of vision anomalies at least twice as high as normally developing children (15). With additional disabilities, many of the children do not respond appropriately to standard vision screening procedures, and modifications need to be made.

Armed with the background information about the existing medical condition, the orthoptic assessment of a child who is vision impaired should include the basic tests of measurement of near and distance vision, evaluation of binocularity and ocular alignment, as well as visual fields and colour vision. Additionally, there should be an objective assessment of how the child functions in unfamiliar indoor and outdoor environments and in differing levels of room illumination. Most importantly, the child's actions need to be observed, as this often brings with it a wealth of knowledge. All orthoptic tests should be performed in a calm and quiet environment without undue time constraints, allowing both the child and their family to feel relaxed. This also allows the family to readily absorb what their child can and cannot do visually, with time for discussion.

Following the assessment, the orthoptist needs to give feedback of his/her findings and consider ways of assisting the child. A vision impairment may have been found, but the child has a lifetime ahead of them - consideration should be given as to what changes need to be done to make it visually easier for them. A young child with visual impairments has little reason to explore the environment. Visual impairments can create obstacles to a growing child's independence (1). There needs to be a focus on the positive - the child may only be able to see N24 size print, but their school work can be enlarged to accommodate this situation.

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Explanations should be given for any head posture that may be used, positioning of objects in a seeing area must be emphasised, room illumination adjusted and expectations of the child need to be acknowledged. Additionally, seating positions within the classroom and the use of clarity and contrast have to be discussed. Often, these issues need a 'common sense' approach.

The orthoptist must think of the visual expectations for the child at their age and suggest how to enhance the environment to a level suitable for the visual acuity. Often, simple changes such as a fluorescent strip on a top step, a bright toy on a simple plain background, or an angled desk is all that is necessary to assist the child. The child with a vision impairment should be assessed at a young age to benefit from early intervention programmes and adaptive technology. These children should be considered by a wholistic approach, and liaising with other health and education professionals is of prime importance.

CONCLUSION

In developed countries, the incidence of CVI, and its resultant vision impairment, is increasing. In agencies such as RBS, children with an array of ocular conditions are assessed, with appropriate intervention instigated. The length of required RBS service provision will vary depending on the cause of vision loss. It is important that the primary reason for the vision impairment is acknowledged so that the expected visual outcomes are realistic, for both the child and their family. As some conditions can be progressive, the family need to be aware of any implications this may have for the future. Orthoptic input is essential in the assessment of the child who is vision impaired. By evaluating the vision standard of a child, through the use of conventional clinical tests, and the functional behaviour of the child, the orthoptist can provide information for, and interact with, other disciplines. In this way, the orthoptist is contributing to the development and well-being of the child so that they may achieve their maximum potential.

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