

# Clinical profile and error of inclusion and exclusion in schools for the blind in Bangalore and a review of literature

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**Purpose:** To determine the causes of severe visual impairment and blindness in children in schools for the blind in the city of Bangalore, Karnataka and to determine the error of inclusion and exclusion from these schools. **Methods:** This was a cross-sectional study. Children in four schools for the blind were subjected to a detailed ophthalmic evaluation. The World Health Organization Program for Prevention of Blindness low-vision form was used to collect data. To know the educational background of children with visual disability of 40% or more (best-corrected visual acuity of  $\leq 6/24$  in the better eye), not in schools for the blind, we collected data by telephonic conversation after procuring their phone numbers from our low-vision clinic. **Results:** One-hundred-seventy-eight children were examined. The major site of anomaly causing blindness in 31% of children was optic nerve, followed by retina (24%), cornea (23%), and whole globe (22%). Avoidable blindness was 35.42%. Thirteen percent of the children with no visual disability were incorrectly enrolled in blind schools. We were able to contact 92 children with a visual disability of  $\geq 40\%$ . Seventy-eight children (84.78%) attended regular schools; these schools were bereft of a specially trained teacher to look after the needs of the blind. **Conclusion:** Avoidable blindness is still a cause for concern. Children should undergo eye-examination before being enrolled in schools for the blind to avoid errors of inclusion. Though integrated education for children with vision disability is a good approach, it requires teachers trained in teaching skills particular to blindness. Education for the visually impaired in India needs a major revision.

**Key words:** Avoidable blindness, schools for the blind, childhood blindness, India, integrated education for the blind

There is a definite change in the pattern of childhood blindness in India; the shift has been from cornea (preventable) as the main cause of blindness to unavoidable causes like whole globe anomalies and retinal pathologies.<sup>[1]</sup> This could be because of the vitamin A supplementation program initiated by the Government of India which has led to a decrease in vitamin A deficiency disorders, particularly blindness.<sup>[2]</sup> Population-based studies are the gold standard for obtaining data on the prevalence, distribution, and determinants of blindness which would help in setting up appropriate health care delivery. Since these studies are time consuming and costly, we make use of data from schools for the blind. The advantage of this data is that a cohort of blind children are easily available. The disadvantages are that children enrolled in schools for the blind, make up only a small proportion of that in the community. It is estimated that in developing countries, only 10% of the blind children attend schools for the blind.<sup>[3]</sup> Children with multiple disabilities are grossly underrepresented.<sup>[4]</sup> The first school for the blind was established at Amritsar in 1887.<sup>[5]</sup> As of 1979, there were 104 schools for the blind<sup>[5]</sup> and the numbers are increasing since then. During routine screening of schools for the blind in our area, we realized that a substantial number of children had no visual impairment and yet enrolled in these schools. We also realized that a large number of children, with

low vision who would benefit from learning Braille, did not attend schools for blind and the regular schools did not teach Braille. This prompted us to conduct this study.

Our objectives were to determine the causes of severe visual impairment and blindness in children in schools for the blind in the city of Bangalore, Karnataka; 2. to determine the percentage of children with no visual impairment enrolled in schools for the blind (error of inclusion); and 3. to determine the percentage of children with a visual disability of 40% and above (best-corrected visual acuity (BCVA) of  $\leq 6/24$  in the better eye) in a low-vision clinic, not enrolled in schools for the blind (error of exclusion).

## Methods

This was a cross-sectional study.

### Ethical considerations

Prior permission was obtained from the respective principals of the schools. Approval from the Institutional review board was obtained. The study adhered to the tenets of Declaration of Helsinki.

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Received: 19-Dec-2020

Revision: 06-Mar-2021

Accepted: 13-Jun-2021

Published: 26-Jul-2021

### Access this article online

#### Website:

www.ijo.in

#### DOI:

10.4103/ijo.IJO\_3725\_20

### Quick Response Code:



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**Cite this article as:** Kemmanu V, Tayde P, Venkatesh R, Sindhu K, Keshavardhini BB, Bhanumathi M, *et al.* Clinical profile and error of inclusion and exclusion in schools for the blind in Bangalore and a review of literature. Indian J Ophthalmol 2021;69:2027-32.

A team comprising of an optometrist, a fellow in pediatric ophthalmology, and other ancillary staff visited four schools for the blind. All students studying in the identified schools were included. They were  $\leq 21$  years of age. Each child was given a child identification number consisting of school code (1 digit), class (2 digits), and roll no (2 digits) forming a five-digit unique identification number. Demographic and data on the age at onset of visual loss, family history, history of consanguinity, and information on previous eye surgery were collected from the students and cross checked with the personal records if required. In situations in which children were not able to answer the question, the data was collected through a telephonic conversation with the parents/caregivers. Information on additional disabilities such as hearing loss, mental retardation, physical handicap, and epilepsy were also obtained.

### Clinical examination

The vision was assessed using the Snellen's/Lea charts. A dilated refraction with cyclopentolate 1% eye drops was performed followed by the anterior segment examination using the magnification of the 20D lens, and fundus examination was done using the indirect ophthalmoscope.

The standard World Health Organization Program for Prevention of Blindness eye examination record for children with blindness and low-vision protocol was used to categorize the causes of blindness and to record findings, using the definitions in the coding instruments.<sup>[6]</sup> The major anatomical site was selected for each eye, and for each child. For each child, the need for optical, surgical, or medical interventions and low-vision aids was recorded and the expected visual prognosis was assessed. Children requiring further investigations, low-vision trial, and treatment were referred to base hospital for further management.

In order to get data on the number of children with low vision attending normal schools, we retrieved their phone numbers from the low-vision clinic register and collected data on their schooling, and if they went to regular schools, we also found out if they had specially trained teachers to take care of them.

The data was fed into the excel sheets on a day-to-day basis, and the descriptive analysis was done using the SPSS software.

## Results

One-hundred-seventy-eight children from four schools for the blind in Bangalore were examined. There were 130 boys (73%) and 48 girls (27%). The age ranged from 5 to 21 years with a mean of 11.69 years. In 137 children (77%), the onset of visual

loss was from birth, in 18 children, the first year of life, in 6 of them after 1 year of age, and 17 children did not know the age of onset of visual loss. Seventy-three children (41%) were products of consanguineous marriage. Fifty-one (28.61%) children had a family history of eye disease. Twenty-two children (12.36%) had other disabilities including hearing loss, epilepsy, physical handicap, and intellectual disability. Thirty-five children (19.66%) had a previous history of eye surgery. About 43% had cataract surgeries and 31% did not know the kind of surgery they had; rest had glaucoma, corneal transplant, and enucleation.

Table 1 shows the uncorrected visual acuities and BCVA in children from the blind schools, according to the WHO categories of visual impairment and blindness.<sup>[6]</sup>

We tried to call 182 numbers from the low-vision clinic register but were able to talk to 92 parents/caregivers [Table 2]. The patients ranged from 5 to 21 years of age. Fifty-three were males and 39 females. All children had a visual acuity of  $\leq 6/24$  in the better eye. Six children attended schools for the blind (one government and five private). Eight of them did not go to school. Seventy-eight children (84.78%) attended regular schools, and none of these schools had a specially trained teacher to look after the special needs of the blind children. Out of the 78 in regular schools, 63 were in private and 15 in government schools. Thirty-four children had disability certificates. Only six children were using low-vision aids.

Table 3 shows the classification according to the anatomical site of lesion in children from the schools for the blind and from the low-vision clinic.

### Data on blind children (BCVA in the better eye of $<3/60$ to no PL)

In children from the schools for the blind, there were 144 blind children. Hundred-and-five were males and 39 females. There were 31 children with whole globe anomalies (eight were unilateral with corneal, uveal, and retinal cause for blindness in the other eye); two children were blind due to uveal cause; both were unilateral with whole globe anomaly in the other eye. There were 34 children with retinal lesions with seven being unilateral, with whole globe, cornea, lens, and optic nerve as the cause for blindness in the other eye. Forty-four children had optic atrophy; one was unilateral with retinal lesion as the cause for blindness in the other eye.

Avoidable blindness (cornea and lens): Thirty-three children were blind due to corneal causes out of which eight were

**Table 1: Uncorrected and best-corrected visual acuities according to the WHO categories of visual impairment and blindness in children from the schools for the blind**

Vision WHO category	Uncorrected visual acuity				Total	Best-corrected visual acuity (BCVA)				Total
	<11 years		>11 years			<11 years		>11 years		
	Male	Female	Male	Female		Male	Female	Male	Female	
6/6-6/18	2	1	6	2	11 (6.18%)	2	1	11	5	19* (10.67%)
<6/18-6/60	3	0	11	3	17 (9.55%)	3	0	8	2	13 (7.30%)
<6/60-3/60	1	1	0	0	2 (1.12%)	1	1	0	0	2 (1.12%)
<3/60-PL	37	11	49	23	120 (67.42%)	37	11	47	21	116 (65.17%)
No PL	5	1	16	6	28 (15.73%)	5	1	16	6	28 (15.73%)
Total	48	14	82	34	178 (100%)	48	14	82	34	178 (100%)

\*There were 19 children with a BCVA of 6/6-6/18 in the better eye. The maximum BCVA in the better eye was 6/6; two children with nystagmus and refractive error (one child also had optic atrophy in OU) improved to 6/6p in both the eyes. Five children were one eyed with a BCVA of 6/6 in the better eye

**Table 2: Best-corrected visual acuities in the better eye, according to the WHO categories of visual impairment and blindness in children from the low-vision clinic**

Vision WHO category	Best-corrected visual acuity in the better eye				Total
	<11 years		>11 years		
	Male	Female	Male	Female	
<i>n</i> =92, Males - 53, Females - 39					
6/6-6/18	0	0	0	0	0
<6/18-6/60	13	10	19	14	56 (60.87%)
<6/60-3/60	3	6	7	1	17 (18.48%)
<3/60-PL	4	2	7	6	19 (20.65%)
No PL	0	0	0	0	0
Total	20	18	33	21	92

**Table 3: Classification according to the anatomical site of lesion**

Site of anomaly	Number of children with problems				Total
	<11 years		>11 years		
	Male	Female	Male	Female	
School for the blind ( <i>n</i> =178)					
Whole globe					
cornea	10	2	15	10	37 (20.79%)
lens	13	2	17	5	37 (20.79%)
uvea	6	4	13	2	25 (14.04%)
retina	1	0	2	0	3 (1.69%)
Optic nerve	9	6	17	10	42 (23.60%)
Refractive error	13	1	27	10	51 (28.65%)
<i>(n</i> =144) Number of children with blindness (BCVA* <3/60)					
Whole globe					
cornea	10	2	12	7	31 (21.53%)
lens	12	2	14	5	33 (22.92%)
uvea	4	4	9	1	18 (12.5%)
retina	1	0	1	0	2 (1.39%)
Optic nerve	8	5	13	8	34 (23.61%)
Refractive error	12	1	22	9	44 (30.56%)
Low-vision clinic ( <i>n</i> =92)					
Whole globe					
cornea	1	3	0	1	5 (5.43%)
lens	1	0	0	1	2 (2.17%)
uvea	0	1	0	0	1 (1.09%)
retina	0	1	2	1	4 (4.35%)
Optic nerve	18	13	31	17	79 (85.87%)
Refractive error	0	0	0	1	1 (1.09%)
Refractive error	0	0	0	0	0 (0%)

\*Best-corrected visual acuity. The numbers do not add up because there are some children with more than one disease

unilateral, with lens, whole globe, optic nerve, and retinal lesion in the other eye.

Among children with lens-related problems, 14 had cataracts (19 eyes), out of which five were bilateral. Two children had bilateral aphakia. Twelve children were pseudophakic (21 eyes). Out of the 25 children with lens-related problems, 18 were blind. Out of the 18, 11 were bilateral and 7 were unilateral. The unilateral cases were blind, since they had a major eye disease in the other eye (one had pseudophakia with posterior capsular opacity, three had retinal detachments, two had dense corneal opacities and one had advanced keratoconus. The

seven children who were not blind were either pseudophakic or aphakic in at least one eye and one child had a unilateral cataract with the other eye being normal. Four out of the seven had mild visual impairment in the better eye and were advised normal schooling. Ten children were advised surgery (three were less than 10 years). More than half (14/25 = 56%) of the children with cataracts had undergone previous surgery. Out of the 14, 8 were blind even after surgery. The blind children had never worn glasses and all of them had nystagmus.

In children from the low-vision clinic, majority (85.87%) had retinal lesions.

Nineteen were blind (11 males and 8 females). Thirteen children were blind due to retinal causes, two – whole globe anomalies, two – corneal causes, and two – uveal causes.

Table 4 shows the BCVA in the better eye, according to the WHO categories of visual impairment and blindness in children with errors of inclusion and exclusion. In the schools for the blind, 23 children (12.92%) were advised a change of school, based on their visual acuity (BCVA of  $\geq 6/24$  in the better eye which constitutes less than 40% disability).<sup>[17]</sup> In the low-vision clinic, 78 children with  $>40\%$  disability attended regular schools. Thirty-two percent of the 78 children going to normal schools had a BCVA of  $<6/60$  in the better eye.

## Discussion

Seventy-three percent of the students in the schools for the blind were male and 27% females. Most of the previous studies conducted in India had about 60% males and 40% females.<sup>[8-15]</sup> Two other studies conducted in Allahabad and Uttar Pradesh had a similar gender ratio like ours.<sup>[16,17]</sup> That gender-based discrimination in healthcare and education for children in India is well established.<sup>[18-20]</sup> It is also possible that parents hesitate to send their girl child to a residential school, far from home. This study found 41% of the children to be products of consanguineous marriage. This comes as no surprise since consanguinity is a common practice in South India.<sup>[21,22]</sup>

About 81% of the children in the school for the blind cohort were blind (BCVA  $< 3/60$  in the better eye). The major site of anomaly causing blindness in about 31% of children was optic nerve, followed by retina (24%), cornea (23%), and whole globe (22%). Table 5 shows the studies from the schools for the blind, from 1995 to 2020, depicting the causes of childhood blindness according to the anatomical site of lesion. We see that most of the studies conducted in India show only a small percentage with optic nerve as the cause for blindness. Two recent studies<sup>[15,23]</sup> show optic nerve as the cause for blindness in 18.09 and 24.8%, respectively. Hypoxic ischemic encephalopathy was the most common cause of childhood optic atrophy in a series of patients seen in a tertiary eye care center in South India.<sup>[24]</sup> However, it is difficult to ascertain why optic atrophy is the main cause of blindness in our study.

A study conducted in Karnataka in 2009<sup>[13]</sup> showed whole globe anomaly as the main cause of blindness (37.5%). This

study shows 21.5% of the blindness to be due to whole globe anomalies. The interactions between genes controlling retinoic acid signaling and maternal vitamin A deficiency during early fetal development are hypothesized to be one cause of whole globe anomalies.<sup>[25]</sup> It is possible that a decrease in maternal vitamin A deficiency in the population has led to decrease in whole globe anomalies.

Our cohort showed 35.4% of avoidable blindness (cornea and lens). Corneal blindness could be due to different causes like infections, trauma, and nutritional. We do not have the data to know the exact etiology. The corneal blindness in this study stands at 23% and is high as compared to the earlier study in Karnataka in 2009 (15%). In fact, it is high compared to many other recent studies in different parts of the country [Table 5]. We are unable to ascertain the reason for this.

Although it is rare, childhood cataract is one of the most important causes of blindness and severe visual impairment in children and is responsible for 5–20% of pediatric blindness worldwide.<sup>[3]</sup> It is evident from our data that more than half of the children who have undergone surgery for cataract are still blind. The main reason for blindness is dense stimulus deprivation amblyopia due to late presentation. Hence, it is crucial to detect cataracts early with adequate screening programs in place. Since cataracts can be congenital, screening will have to start at birth. We would like to suggest the following regulations. It is said that 83% of the deliveries in India occur in institutions.<sup>[26]</sup> The first healthcare personnel to examine the baby is the pediatrician. Red reflex testing which is an important component of new-born screening<sup>[27]</sup> should be mandatory and performed by the pediatrician before discharge. Accredited social health activist workers, anganwadi workers, and auxiliary nurse midwives should be trained to look for white or grayish reflex in the pupil with the help of a torch light. The vaccination coverage in India is 62%.<sup>[28]</sup> The visit for vaccinations must be made use of and the child should be evaluated for eye health. The vaccination cards, in addition to having the schedule of the vaccinations, must also have a slot dedicated for eye evaluations, which can help in confirming if the eye evaluation is accomplished.

We found that 13% of the children enrolled in the schools for the blind had a visual acuity of  $\geq 6/24$  in the better eye [Table 4]. A recent study in Uttar Pradesh<sup>[17]</sup> found that 22.6% of the children with good visual acuity enrolled in schools for

**Table 4: Best-corrected visual acuities in the better eye, according to the WHO categories of visual impairment and blindness in children with errors of inclusion and exclusion in the schools for the blind**

BCVA* in the better eye	Error of inclusion (Children with no vision disability (BCVA of $\geq 6/24$ in the better eye) enrolled in schools for the blind $n=23$ )					Error of exclusion (Children with vision disability (BCVA of $\leq 6/24$ in the better eye) not enrolled in schools for the blind $n=78$ )				
	<11 years		>11 years		Total	<11 years		>11 years		Total
	Male	Female	Male	Female		Male	Female	Male	Female	
6/6-6/18	2	1	11	5	19	0	0	0	0	0
6/24	1	0	2	1	4	-	-	-	-	-
<6/18-6/60	0	0	0	0	0	13	10	16	14	53 (67.95%)
<6/60-3/60	0	0	0	0	0	1	6	4	0	11 (14.10%) <sup>#</sup>
<3/60-PL	0	0	0	0	0	4	1	5	4	14 (17.95%) <sup>#</sup>
No PL	0	0	0	0	0	0	0	0	0	0
Total					23					78

\*Best-corrected visual acuity. Three children in the category with BCVA 6/6-6/18, had 6/6 in OU. All three had high-refractive errors. One child had 6/18 BCVA in OU and had oculocutaneous albinism. <sup>#</sup>32.05% of the children with a BCVA of  $\leq 6/24$  in the better eye, in normal schools, had a BCVA of  $<6/60$  in the better eye



**Table 5: Studies from the schools for the blind showing the causes of childhood blindness according to anatomical site of lesion. (1995-2020)**

	Whole globe	Cornea	Lens	Uvea	Retina	Optic nerve	Others	Avoidable causes
9 states, 1995	27.9%	26.4%	12.3%	5.8%	20.7%	5.9%	0.9%	47%
Andhra Pradesh, 2000	26.9%	24.3%	7.9%	3.4%	31.1%	4.9%	4.47% (CVI, disorganized globe)	37.4%
Delhi, 2003	27.4%	21.7%	10.9%	8.8%	15.1%	10.6%	0.8% (Pathological myopia, CVI)	43.5%
Maharashtra, 2007	41.3%	22.2%	6%	-	11.2%	-	-	34.5%
North-East India, 2008	36.1%	36.7%	10.9%	-	5.8%	5.3%	3.2%. (pathological myopia, KC, CVI, nystagmus)	48.5%
Karnataka, 2009	37.5%	14.9%	11.4%	4.4%	19.9%	5.7%	-	27.8%
Andhra Pradesh, 2012	41.4%	8.1%	9.9%	4.5%	18.9%	6.3%	10.8% (amblyopia and nystagmus)	40.9%
Allahabad, 2015	54.44%	24.45%	10%	1.11	3.33%	6.67%	-	37.7%
Chennai, 2017	1.99%	15.6%	12.9%	3.6%	18.2%	24.8%	10.9% (indeterminate) 6.6% (congenital glaucoma)	31.09%
Uttar Pradesh, 2018	40.3%	26.4%	6.9%	11.1%	8.3%	4.2%	-	24.8%
Pune, 2019	31.6%	10.8%	4.9%	-	12.4%	5.9%	14.2% (nystagmus, pthisis bulbi)	15.7%
Andhra Pradesh and Telengana, 2020	32%	11.2%	17%	0.4%	26.6%	7.3%	5.4% (CVI, amblyopia)	37.1%
Uttar Pradesh, North India, 2020	21.40%	8.51%	4.26%	-	40.42%	18.09%	-	23.4%
Present study (2020)	21.53%	22.92%	12.5%	1.39%	23.61%	30.56%	-	35.42%

the blind. We feel that this would cause an unnecessary expenditure on the already meagre resources for the education of the visually impaired. One of the disadvantages of the school for blind is the marginalization and exclusion of these students. This may result in inferiority complexes among them and their parents. Hence, inclusive education was established in 1971, with the aim of integrating children with special needs and normal children, through mainstream schooling.<sup>[5]</sup> In this context, we find it surprising that children with normal visual acuity in one or both eyes prefer to stay in schools for the blind. Out of the 23, 6 children had a normal better eye with the worse eye diagnosis of globe anomaly in 3, cataract in 1, and corneal opacity in 2 cases. It could be possible that there is a confusion regarding the inclusion of one-eyed persons under the category of blindness, in spite of the Ministry of Health's notification that a person with <40% disability is not eligible for a disability certificate.<sup>[29]</sup> In reality, persons with a BCVA of 6/6 in the better eye and <3/60 to no PL in the worse eye are considered to have a 30% disability.<sup>[7]</sup> Nine children improved with refractive error correction in either eye. The importance of correcting refractive errors, even in the presence of other major morbidities like microphthalmos, retinal dystrophies, or optic atrophies, cannot be overemphasized. It is important that children get a detailed ophthalmic evaluation before they get enrolled in blind schools. It must be made compulsory to get a vision disability certificate at the time of admission, so that a wrong recruitment can be avoided.

Education for the visually disabled in India is inadequate and far from organized. Out of the 92 children with a BCVA of  $\leq 6/24$ , 78 went to regular schools which did not have any specially trained teacher. Out of the 78, 25 (32%) had a BCVA of <6/60 in the better eye. These children would definitely benefit from attending schools for the blind. We have seen children with severe visual impairment, in their teens, struggle to read and write; they are unfortunately not trained in Braille and other skills particular to blindness. Not being trained in

Braille is especially disastrous for children with progressive blindness (retinal dystrophies). We agree with the fact that integrated education (bringing disabled children into the main stream of education) is economically viable, psychologically superior, and socially acceptable, but it does not mean that blind children can be simply placed in a regular classroom.<sup>[30]</sup> It requires the provision of teachers trained in teaching skills particular to blindness such as auditory perceptual training,<sup>[31]</sup> Braille reading and writing, use of reader services, and orientation and mobility. We would like to add here that perhaps the phrase "error of exclusion" from a schools for the blind would not be entirely appropriate, if we consider that inclusive education is the gold standard of educating children with low vision; in fact, these children are supposed to go to a regular school! The problem with our system is that a proper education is not possible due to the absence of infrastructure and trained personnel required to educate children with low vision. This is evident from our study; not a single child went to a school that had a teacher trained to educate children with low vision. Hence, a child with low vision in India definitely gets a better education, in a blind school rather than in a normal school with no trained personnel and infrastructure. Hence, we feel that we are justified in using the term "error of exclusion" from the schools for the blind. Inappropriate inclusion of children without vision disability into schools for the blind and children with vision disability into regular schools causes an impairment of the overall growth and development in children.

In our study, only 6 of the 92 children used low-vision devices. This could be because of the cost and lack of motivation to use the device.

## Conclusion

In conclusion, the data from this study shows that avoidable blindness is still a cause for concern. More than half of the children with cataracts were blind even after surgery. We need

to lay more emphasis on screening for eye diseases in children at a young age. Admission into schools for the blind needs to be more organized. Inclusive education has to be promoted, but with especially trained teachers and facilities provided for educational materials like Braille.

### Acknowledgment

We would like to acknowledge the help rendered by Dr K. Nagaraj, professor in Asian College of Journalism, Chennai in providing a broad overview of how to go about the study.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

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