Childhood Blindness ……..

India prepares to deal with it.

ORBIS

saving sight worldwide

Contents

[NOTE: THIS REFERENCE SECTION NEEDS TO BE DONE, AND SOURCES NEED TO BE CITED THROUGHOUT. SD]

INTRODUCTION

For any child to be blind is a life-long challenge. In India, 400,000 children are blind from conditions, which could have been either prevented or cured, and this is the challenge faced by everyone dealing with eye care for children.

Blindness is found everywhere, not bound by any boundaries of place, person or time. Anyone can be affected irrespective of status, general health, and age. The total number of individuals who are avoidably blind and impaired increases every year, and this number is expected to double in another 30 years if the pace remains the same.

There are about 1.5 million children in the world who live with blindness or visual impairment. A more disturbing fact is that 73% of those affected are from low-income countries. One common factor true in these countries is poverty. When a child becomes blind early in life he or she spends any more years with the disability than someone who becomes blind in old age.

For every country, children are great assets, and the direction of the future. Thus, we need to protect them from disability, poor health, and other threats to their well being. Control, prevention, and treatment of avoidable childhood blindness is an essential part of this effort. There is also a need to educate the children with untreatable blindness. They can be assisted to lead independent, functional, and productive lives. We at ORBIS are committed to assisting these children. We have developed this document to guide us in our goals addressing Childhood Blindness.

[NEEDS LATTER FROM KATHY ALSO? SD]

Magnitude of the Problem

Childhood blindness means an individual under 16 years of age with corrected visual acuity in better eye of less than 3/60 or a central visual field of less than 10 degrees. Those children with less than 6/60 are not classified as "blind" but as having "serious visual impairment" and they need low vision services. Therefore, the total number of children requiring services is larger than the estimated number of blind children alone. Out of total blindness in the world, 5 percent is childhood blindness. There are 1.5 million children blind in the world, about 73 percent of whom live in low-income countries. Around 500,000 children become blind every year in this world. In India we estimate there are around 400,000 blind children and an equal number who require eye care services to improve quality of life.

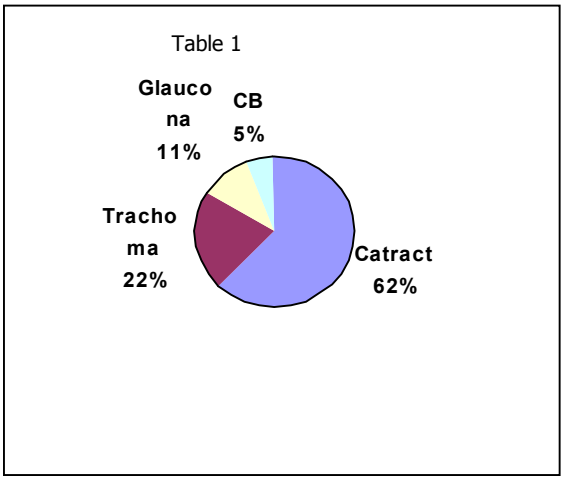
Childhood blindness is different from other blindness in that it results in many more years of blindness in life. In India the average life expectancy is around 60 years. The child who is blind thus spends 60 years with the disability. To make their lives independent and productive, education and rehabilitation programs may be undertaken. These social and educational issues stemming from childhood blindness make the problem one of great magnitude.

The estimated overall global prevalence of childhood blindness ranges from .4 to 1.2 per 1000. Although there are great variations within countries, these figures are generally lowest in industrialized countries and highest in underdeveloped poor countries.

In India, prevalence of childhood blindness averages around 1.0 per 1000. India is a continent where every state is like a separate country with unique language, culture, industry, and economic status. The variation between states is very high; some states are similar to any other developed country and some are similar to many of the poorest countries of the world. Therefore, the prevalence of childhood blindness in India varies. There are no epidemiological studies with sound methodology done in India to provide exact data; that would require effort and resources that would be better spent on direct services. Therefore, while there are reports from a few surveys and cross-sectional epidemiological studies in childhood blindness, these figures can not be extrapolated and extrapolated to the rest of the country because of diversity in different states. After reviewing all the reports available, however, 1.0 per 1000 is a reasonable estimate of childhood blindness for India.

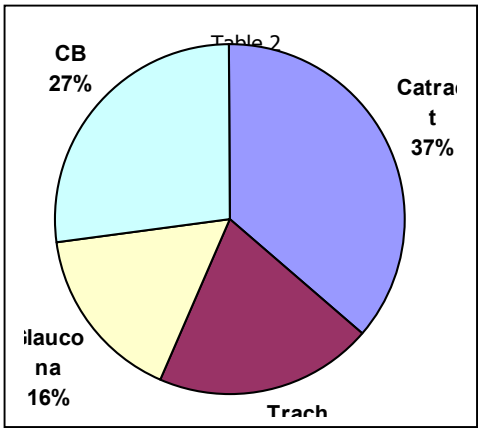
However, neither prevalence nor incidence is sufficient to gauge the problem of childhood blindness in India. To describe the problem in full perspective, one needs only consider the total number of years with disability sustained when blindness begins in childhood and the loss of productive years due to childhood blindness.

Table 1



Total number of people affected

Table 2



Total number of years of blindness

The pie diagrams above compare the total number of people affected by specific vision conditions to the total number of years one is blind from the same causes. Childhood blindness, which has least prevalence in Table 1 (5%), becomes the second most important cause of blindness when it is calculated as the estimated total years people are blind from any of the conditions responsible for blindness.

Various Descriptions of the Magnitude of the Problem

Prevalence surveys are one of the methods to measure how big the problem is. However, such surveys are very time-intensive, requiring many persons trained in the survey methods to travel extensively through rural and often remote areas. Once these prevalence figures are ascertained, they may shift quickly due to a change in demographics or medical care, and these shifts may not be reflected in the statistics gathered. Thus, prevalence rates are fluid and often not descriptive of true needs in a given geographic area. Once completed, the costs in personnel hours of doing such a survey may be deemed better spent by providing services to persons already identified as needing those services.

There are alternatives to prevalence studies available, which yield useful information on prevalence and incidence figures and also hasten the process of getting much-needed services to people needing them. These faster methods can provide a sense as to the extent of vision problems in any community.

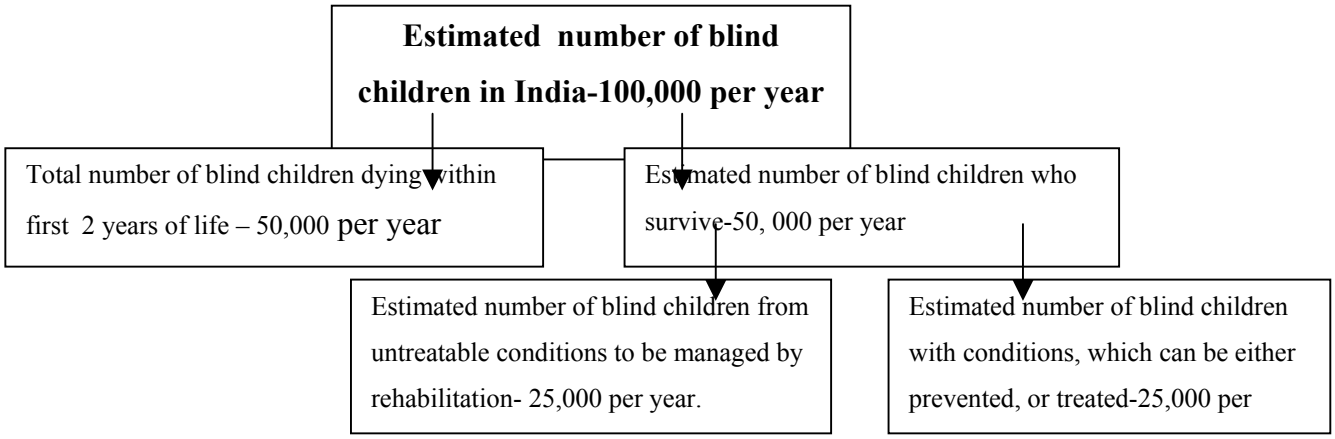
In India there are no useful registers of blind persons as in some industrialized countries. Studies of schools for the blind have been conducted as a way to get information on causes of blindness. Such studies have proven very useful.
Community based rehabilitation programs also disseminate information on numbers of blind children reside in given districts. In these ways, rough estimates can be obtained. Qualitative research helps in again knowing at least something about childhood blindness problem in the community. The methods used are key person interviewing, focus group discussion and mapping.

Child Survival and Blindness

It is generally accepted thought that the global incidence of childhood blindness is 1,500,000 children. In India we estimate 100,000 new cases of childhood blindness every year. Childhood blindness is a reflection of the health status of children in any given area. Child health statistics include figures such as average height, weight, head circumference, morbidity, and threshold survival weights of neonates. In countries in which children exhibit good health conditions, access to medical services, and adequate nutrition, all child health statistics, including blindness prevalence statistics, reflect this overall health status. Likewise, in countries in which the health status of children is poor, child development statistics reflect this as well. There is a relationship between infant mortality and prevalence of childhood blindness, and the figures increase and decrease concomitantly.

The above graph [NOTE: GRAPH MISSING. SD] shows the linear positive relationship between blindness and 0-5 mortality. It is very clear that as the prevalence of blindness increases, mortality 0-5 also increases. Out of 100 typical children in any developing country 25 to 30 children die before five years of age. Of 100 blind children, 50 to 60 children die in first five years if their life. This means that child survival rates can be improved by dealing holistically with childhood blindness, and vice versa. When children are prevented from becoming blind, their chances of survival and overall increased health status also improve.

Flow diagram showing load of childhood blindness per year in India

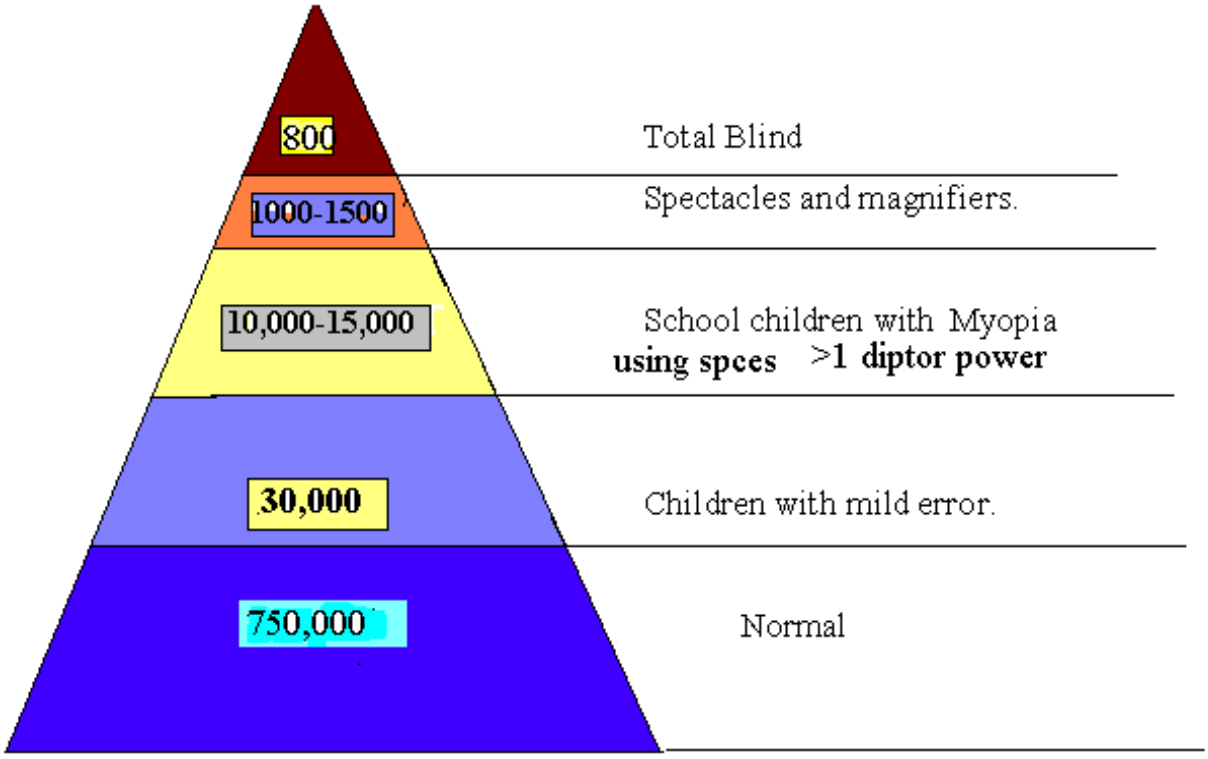


[NOTE: CITE THE SOURCE FOR THESE FIGURES OR ELSE DELETE THEM. SD]

In India, around 100,000 children become blind every year. Out of these 50 percent die due to causes of blindness and 50,000 children survive. Out of these half suffer from untreatable type of blindness, which need to be managed through "Rehabilitation". Remaining 50 percent are either treatable causes of blindness or preventable. Therefore, the total number of blind children in India who need to be managed is 50,000 per year. So, every year 50,000 blind children are added to the existing pool/load of childhood blindness.

How much blindness is there per district in India?

In India, a district of approximately 2 million is predicted to have the following breakdown in childhood blindness: en (40 This



population would consist of 800,000 children (40% of the population). Of these, at 1/1000 prevalence of childhood blindness, there would be around 800 blind children in the district and 2,400 children with high refractive error. Of these estimated 800 blind children, 400 (50 percent) would be blind due to untreatable conditions. The remaining 400 (50 percent) children in a district are expected to be blind from conditions which are preventable or treatable. This suggests that blindness could be avoided in 400 children by intervention projects undertaken at grass roots levels. A large proportion of children need only to have cataracts removed and then get proper refractive correction. As shown in the above diagram, around 30,000 children would require minor correction for refractive error, managed through screening and provision of high quality, low cost spectacles. The district would also have about 1000-1500 children who need spectacles or magnifiers.

Conditions Responsible for Childhood Blindness

The conditions responsible for blindness in children are classified in two groups as follows:

- First, using a descriptive anatomical classification where the site in the eye most affected is described, and
- Second, etiological classification based on the time of onset of the condition.

The anatomical classification gives information on all children who are blind, a figure, which can be used to assess the extent of vision problems in any community. The etiological classification is more useful for planning preventive measures, although to obtain reliable data on etiological information is more difficult

Causes of Childhood Blindness by Anatomical Site	
27 percent	Retina
19 percent	Cornea
18 percent	Globe
13 percent	Lens
10 percent	Optic Nerve
06 percent	Intra Ocular Pressure
04 percent	Other
03 percent	Uvea

[NOTE: THE ABOVE AND BELOW SHARTS ARE CATEGORIZED IN GROUPS THAT ARE NOT MUTUALLY EXCLUSIVE. THIS NEEDS TO BE CLARIFIED. SD]

Causes of Blindness by Etiological Category: -	
40 percent	Unknown
30 percent	Hereditary
20 percent	Childhood
07 percent	Perinatal
03 percent	Intrauterine

Major causes of blindness in children

There is marked difference in causes of blindness in children between different states in India. The overall causes are as below-

Different conditions responsible for Childhood Blindness

- Cataract
- Glaucoma
- Retinopathy of prematurity
- Refractive error
- Uncorrected [NOTE: UNCLEAR. SD]
- Corneal scars
- Uveitis

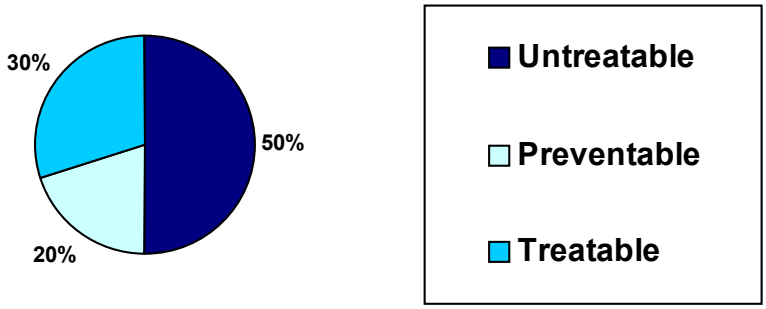
Conditions like Vitamin A deficiency, ophthalmia neonaturum, and sometimes dangerous traditional eye medicine are more common causes of childhood blindness in the states which are not doing well in general development, with poor socioeconomic conditions and indicators of poor maternal and child health. These states include Bihar, Orrisa, and Rajasthan. In contrast, conditions like hereditary retinal dystrophies, retinopathy of prematurity, and congenital cataract are found more frequently among the causes of childhood blindness in the states which are doing well as far as the above-mentioned criteria are concerned. These states include Tamil Nadu, Andhra Pradesh, Maharashtra, and Kerala.

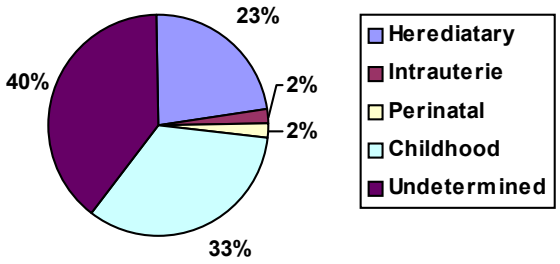
Causes of Childhood Blindness in India by Etiological Category:

Etiological category	Percent	n
Hereditary	23	92,000
Intrauterine	2	8000
Perinatal	2	8000
Childhood	33	132,000
Undertermined	40	160,000
Total	100	400,000

Above table describes the distribution of blind children according to etiological category. It seems that in India hereditary, childhood and undetermined type of blindness constitute very big number as compared to intrauterine and perinatal.
[NOTE: THE ABOVE SECTION UP TO THE TITLE IN BOLD CONTRADICTS THE PRIOR DATA. FOR ALL DATA, CITE SOURCES, GIVE DATES. THE ABOVE GRAPH AND PARAGRAPH MIGHT BE BETTER DELETED. SD]

The causes of Childhood Blindness can be classified as 1) untreatable 2) preventable and, 3) treatable. The preventable and treatable conditions of childhood blindness constitute fifty percent of total blindness. The remaining 50% is untreatable childhood blindness which is managed by education and rehabilitation.





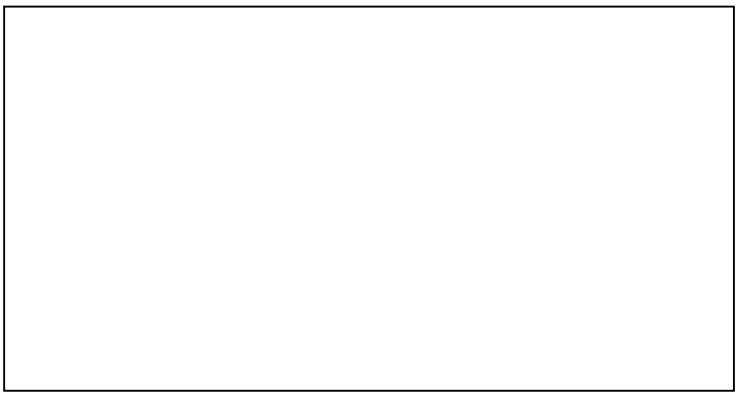
There is regional variation in avoidable childhood blindness, and the relative importance of causes also varies considerably from region to region. Overall 50% of childhood blindness is avoidable. However, a significant proportion of unknown causes represent conditions which are not be easily diagnosed and are often misdiagnosed, such as congenital rubella syndrome. This 50%is therefore, the minimum estimate of avoidable childhood blindness. The true number is probably closer to 80%.

Socioeconomic development and availability of health care services determine status of childhood blindness causes. Therefore, the causes vary over time in response to change in the development and introduction of health interventions. For example, retinopathy of prematurity was a major cause of childhood blindness in Europe and the United States during 1950's. Now it is expected that in next five years India may go thorough the same experience with extensive development of neonatal technology, maternal and child health care, and resulting decrease in surviving threshold birthweights India. Once a country's infant mortality rate drops below 60 per 1,000, this is the point at which retinopathy of prematurity begins to occur, reflective of the increased resources to sustain life of very premature infants. It is predicted that all developing countries in transition will develop different patterns of childhood blindness as their status of children shifts, just as patterns will emerge within countries.

It is beneficial also to consider the conditions responsible for childhood blindness based on the services needed to control and prevent them at different levels of health care. For example, the following breakdown provides another perspective, that of treatment options:

- Causes, which can be, managed at the first level such as Vitamin A supplementation, refractive error.
- Causes that can be managed at the secondary level such as congenital cataracts, glaucoma.
- Causes which can be managed at the third level such as strabismus, retinopathy of prematurity.

Congenital Cataract



[NOTE: THIS CHART IS EMPTY. SD]

An estimated 200,000 children are blind from cataract in the world. The childhood cataract prevalence is reported to be 1 to 15 per 10,000 children. Cataracts present at birth are estimated to be 1 to 3 per 10,000 births in developed countries. This figure is much higher in developing countries due to exposure to rubella and other etiological factors. It is expected it to be 5 per 10,000 births in India.

In India about 15 percent of children in schools for the blind have cataract, and similar numbers are found in community based assessments. Therefore, out of the 400,000 total of blind children in India it is expected that 60,000 children are blind because of bilateral cataract. It is estimated that the incidence of bilateral cataract in children is around 10 cases per million per year; it is expected that 10,000 new cases are added to the existing number annually.

Out of 100 cases of bilateral cataract the major causes in India are:

Rubella	25 percent
Heredity	25 percent
Unknown	50 percent

How to manage the problem of Cataract in India?

Cataract is a condition where 25 percent of cases could be prevented from going blind, as the cause is rubella. With rubella vaccine available such prevention is possible. Even if vaccine is not available to all areas, there is treatment available. Therefore, no child needs to remain blind in a community because of bilateral cataract. To achieve this a good referral system is needed, sending cases from primary to tertiary care through local intervention programs. This can be done with v in the community trained in vision work. One volunteer would identify children with vision problems and refer them to the nearest paediatric ophthalmology treatment center. The paediatric ophthalmologist would treat these cases. It is observed that in India children with bilateral cataract present very late for treatment, the mean age being 5 years. For the results of the treatment to be good it is essential to examine newborn babies for cataract to assure early referral. Simple education can also be given to the traditional birth attendants and midwives. In children under one year with bilateral dense cataract, lensectomy is the treatment of choice. In children over one year, cataract can be extracted by aspiration. Full aphakic correction with spectacles can be done. The children who have undergone cataract surgery need to be followed by a paediatric ophthalmologist. Each child requires frequent retinoscopy and change of spectacle lenses throughout infancy. The use of an IOL can be considered after two years of age, although more information is still needed on long-term efficacy of IOLs in infants.

To summarize, cataract is treatable and India can manage this problem with inputs at two levels. At the first level, the cases of cataract (both congenital and traumatic) in children should be detected as early as possible. At the second level, these

identified and referred cases should be treated surgically and followed up by paediatric ophthalmologist at the paediatric ophthalmology treatment center.

Cataract due to Rubella

Rubella is an epidemic disease in most parts of the world. However, the majority of females contract the disease in childhood, thus acquiring natural immunity. Congenital Rubella Syndrome (CRS) is systemic; ocular abnormalities result when the virus crosses the placenta in non-immune mothers. Recent reports based on different studies in India suggest that approximately 1 infant out of 4 with bilateral cataract is positive for IgM antibodies due to rubella infection. Women affected during first trimester of their pregnancy with rubella infection can give birth to a child with range of systemic abnormalities including cardiac problems (in 50% of cases) deafness (in 25% of cases). Because of these multiple disabilities, the majority of children with CRS die before they are five years old. Of the cataracts due to rubella, 75% microphthalmic and 25% have a transitory corneal opacity. Thus, the eye problems related to CRS include cataract, microphthalmia, corneal opacities, changes in retinal pigment epithelium, and glaucoma.

Management of Congenital Rubella Infection: Serological surveys in India indicate that up to 45 percent of women of childbearing age are susceptible to rubella and potentially at risk of infection during pregnancy. Since this is a preventable condition through rubella vaccination, there are two strategies to pursue, as follows:

1) Immunize all females 12 to 13 years old. The aim is to protect at risk individuals who may not have acquired natural immunity through rubella infection in childhood.
2) Universal immunization with rubella vaccine infants at nine months with measles vaccine with 80% coverage (ideal is 90%).

To complete Strategy 2 requires very high coverage in order to maintain a minimum of 80% immunity over many years. If the immunity level decreases, more women are placed at risk of acquiring rubella in pregnancy. This once more leads to an increase in the number of children born with CRS.

(Photograph of a child with cataract due to rubella infection).

[NOTE: PHOTE MISSING]

Retinopathy of Prematurity

Retinopathy of Prematurity (ROP) is a potentially blinding disease first described in the early 1940's. Earlier it was known as Retrolental Fibroplasia. This is a condition where vasoproliferation of the retina occurs in premature children. This disease is seen in countries and areas where socioeconomic status is moderate to high and where maternity and neonatal services are quite well developed. In these areas, more premature babies survive due to increased neonatal technology. India is now in a phase in which parts of the country have neonatal advances equivalent to those in developed countries. Therefore, ROP is predicted to become a far greater problem for India in the future if no intervention is done. Today increasing numbers of ROP is a high priority of childhood blindness in India, because of increasingly extensive and well-developed maternity and neonatal care.

Classification of Retinopathy of Prematurity:

ROP is classified in five stages:

Stage I	White demarcation line between vascular and avascular retina.
Stage II	Ridge demarcation line is raised.
Stage III	Ridge with extra retinal fibrovascular proliferation.
Stage IV	Sub-total retinal detachment.
Stage V	Total retinal detachment.

PLUS Disease - Retinal vessel tortuosity, vitreous haze and pupil rigidity.

(Picture of retinal detachment)

[NOTE: ABOVE PICTURE IS MISSING. SD]

Etiology of ROP

ROP still remains poorly understood. While all the risk factors have net yet been identified, it appears that the combination of low gestational age and supplemental oxygen given in the neonatal course are the two most significant contributors to the condition. Technology in neonatology has expanded faster and become more available in remote areas than the parallel advances in ophthalmology for neonates at risk. As a result, premature infants receiving the highest level of neonatal care are highest risk for the condition. Studies have investigated maternal risk factors for ROP, yet it still appears that prematurity/low gestational age/low birthweight plus supplemental oxygen remain the strongest risk factors for ROP.

Severe ROP is found in infants who belong to one of the following groups:

1) Birth Weight <1500 gms. or 3.3 pounds
2) Gestational age at birth <31 weeks.

Other causes are fluctuating or high oxygen levels and other systemic illness during the neonatal course.

Management of Retinopathy of Prematurity:

ROP is not entirely preventable due to the levels of oxygen necessary to sustain life in vulnerable premature infants. However, it can be prevented in a reasonable number of premature babies with proper screening done at intervals of two weeks. The screening begins shortly after birth. The critical time window for treatment is extremely small, approximately two to four weeks. Therefore, the timing of screening becomes even more critical.

For control and prevention of ROP we need to involve other specialties than ophthalmology alone, including neonatology, paediatrics, obstretics, neonatology, and midwifery. All need to work together to assure the following measures are undertaken:

- Good antenatal care- to prevent low birth weight/premature birth.
- Good neonatal care- to monitor oxygen therapy and arterial oxygen tension.
- Good ophthalmology care- to take measures to detect Stages 3 ROP, if found to treat it with cryotherapy or laser, and to provide or refer to low vision services and follow-up care.

India needs following information from neonatal intensive care units: -

a) Survival of babies weighing 1000-1500 grams.
b) Survival of babies weighing <1000 grams.
c) Prevalence of ROP (by stage) in each of these groups.

The twelve ophthalmology hospitals in India are most logically identified as centers with facilities for treatment of Retinopathy of Prematurity. These are shown in this map. [NOTE: NO MAP. SD] All these centers need to be connected through Central Registry for Retinopathy of Prematurity. This would prove very effective in the overall management of Retinopathy of Prematurity and also yield valuable information on the course of the disease.

[CURRENT STATUS OF THIS? SD]

Corneal Blindness

Childhood blindness due to corneal scars leads to 25% of total childhood blindness in many areas of the world. In India, though the schools for the blind studies have reported cataracts in 23% of their cases, it is not reported in younger children. There are minimal cases of corneal scars found because of Vitamin A deficiency in India, and these are found only in a few tribal areas.

It now seems clear that improving the vitamin A status of deficient children would not only prevent 5 million to 10 million cases of xerophthalmia and half a million children from going blind each year, but save a million or more lives annually as well.

\- Alfred Sommer.

[NOTE: NEED DATE ON THE ABOVE. SD]

Etiology:

Vitamin A deficiency can be a result of an inadequate diet, malabsorption of nutrients, or infections. Under normal conditions, the rods and cones (photoreceptors of retina) produce the photosensitive pigment rhodopsin that responds to light and triggers neural impulses, which take the message to the brain. Rhodopsin is also responsible for vision under low levels of illumination (also known as night vision or scotopic vision) and it contains vitamin A. Therefore, night-blindness occurs as a first symptom in vitamin A deficiency. Another function of vitamin A is the maintenance of differentiation in epithelial cells. Hence, vitamin A deficiency causes changes in both the epithelial cells of eye's cornea and the retina itself.

The important signs of vitamin A deficiency are:

XN	=	Night-blindness	(after 2 years age group)
X1B	=	Bitot's spots	(3 to 10 years of age group)
X2	=	Corneal xerosis	(6 months- 4 years age group)

X3	=	Corneal ulcer	(6 months –4 years age group)
XS	=	Corneal scar	(1 year and above)

[NOTE: THE SECTIONS ABOVE AND BELOW NEED MORE EXPLANATION, THEY ARE SOMEWHAT UNCLEAR. SD]

Vitamin A deficiency is both a contributor and determinant of condition leading to childhood blindness.

Management of Corneal Blindness

Corneal scars are treatable but the donor corneas available for paediatric eyes are very few in number. The tissue required for corneal grafting in children needs to be harvested at the time a person passes away. For cultural, spiritual, and traditional reasons this process is not widely accepted in India. Therefore, there is a problem in securing enough corneas to meet the needs for keratoplasty in children. Once done, the graft is more often rejected in pediatric cases than in adult cases. Therefore, it is very important that corneal scars should be prevented in all childhood blindness efforts rather than treating cases with corneal transplants. The various Health Care Programs with agenda of "Child Survival" deal with this problem. [NOTE: EXPLAIN THESE. SD] The prophylactic and therapeutic dose distribution of vitamin A solution and nutrition education in the community remains the best possible intervention to prevent corneal blindness

Prevention and control of Vitamin A deficiency: Short term strategy:

Vitamin A Supplementation

Prophylactic Dose Schedule:

- 6000 I.U. orally to pregnant women after 20 weeks of pregnancy (higher dose should not be given as they have teratogenic effects)
- 200,000 I.U. to the mother immediately after delivery so that breast milk contains adequate amount of vitamin A
- 100,000 I.U. to infants (below 1 year)
- 200,000 I.U. every six months till the age of 6 years

Therapeutic Dose Schedule:

200,000 I.U. injected intramuscularly, two doses on subsequent days to those children with symptoms of vitamin A deficiency or who are suffering from measles, protein energy malnutrition, and severe diarrhoea; a third dose to be repeated after one month. Vitamin A supplementation in India is carried out by primary health care workers (CSSM, ICDS, [EXPLAIN THESE ACRONYMS. SD] Nutrition rehabilitation program, Nutrition supplementation program [IF THESE ARE FORMAL GOVERNMENTAL OR NGO PROGRAMS, EXPLAIN THEM. SD]).

Prevention and control of Vitamin A deficiency: Mid term strategy:

To remove the risk factors, which lead to vitamin A deficiency, it is optimal to complete measles immunization, diarrhoea control, and ORS therapy. [NOTE: EXPLAIN THIS; IS IT ORAL REHYDRATION? SD]

Prevention and control of Vitamin A deficiency: Long Term Strategy:

To improve nutrition status of children and pregnant mothers through nutrition education, the following strategies are found to have an impact:

- Health education about Vitamin A rich food available in the area given to caregivers and children
- Motivation and materials for growing deep green leafy vegetables and papaya trees in home gardens
- Improving nutrition education to children in school programs.

In control of vitamin A deficiency it is very important to look into the logistics of vitamin A supplementation and make it available at al levels of health care facilities. In India this includes getting information to rural and often remote areas, dealing with the challenges of many languages, facing lack of literacy in general, and considering alternatives for families in dire poverty, including those with small choice in available food. Treatment methods, to be effective, will need to address these dissemination challenges in innovative and culturally appropriate ways in order to assure impact of health education programs. These methods may include use of picture cards, distribution of dietary supplements, and outreach to the most remote areas of the country.

Corneal Scars due to Measles:

Blindness following measles is result of different etiological conditions. Children with measles have conjunctivitis and many of them develop punctate keratitis. This is usually self-limiting, involves only the corneal epithelium, and usually heals without residual damage to cornea if the eye is closed after application of proper antibiotic ointments. However, the non-availability of proper antibiotics leads to use of traditional eye medicines, which are easily available. The caregiver, in fear of the child going blind, may try a TEM. [NOTE: IS THIS TRADITIONAL EYE MEDICINE? WRITE THIS OUT. SD] This may be more harmful and even erode the compromised epithelium, causing physical trauma due to toxic chemicals, and bacterial or fungal pathogens. This then leads to corneal scarring and blindness. With measles, vitamin A deficiency is usually found. To control this requires both immunization and proper antibiotics (and knowledge in their use) at village levels.

Eye Banking in India

While it has been stated in the previous sections that corneal grafting is not the treatment of choice with children having corneal scars. Eye Banking in India is an important issue in itself and therefore it is addressed in this section. The problem of corneal blindness in India remains very high and a large number of corneal blind people can benefit from corneal transplantation. The lack of corneas is the main hurdle to be overcome. Some eye banks are retrieving only 50 to 100 corneas per year, so there is definite need to improve. This should be done through High Cornea Retrieval Program, as follows:

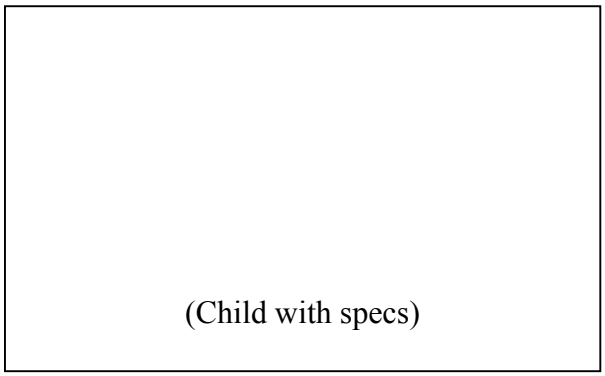
- First, the focus on "pledging" needs to be shifted. The message of eye donation should continue after a person fills the pledge forms. Today the pledge forms number in the millions and yet retrieved corneas number only in the thousands. Changes need to take place.
- The "grief counseling" in hospitals should be extended to more hospitals where terminally ill patients are admitted. These "grief counselors" help families make the decision to donate eyes of their ill relatives after death.
- The tissue removal and proper preservation can be best organized in a hospital location. Storage can be done at the main eye bank in the area. Collected corneas then can be used by eye care hospitals doing corneal transplants.

To summarize, to receive enough corneas from eye banks, there is a need for an excellent operational infrastructure with trained manpower at all levels of eye banking beyond only the public awareness effort. There can be centers attached to hospitals with volunteer or part time staff to counsel and motivate the families of ill patients to donate corneas after the loss of their family member. These centers can be connected to the nearest eye bank, which handles all tissue evaluation, preservation and distribution. Also, one Eye Banking Training Center can be established for each region to train the staff of eye banks in the area. In India, to date, there are nine eye banks who together retrieve more than 500 corneas per year. This volume should be the targeted goal for each eye bank in India.

Indian map showing destinations of nine efficient Eye Banks in India.
[NOTE: MAP MISSING. SD]

At the same time the risk of overexpansion of eye banks in India should be carefully monitored. The fragile tissues, if not properly preserved, are often rejected after transplants. These occurrences create problems for not only the patient and doctor, but for the reputation of the eye banking movement itself.

Refractive Error



[NOTE: PHOTO MISSING. SD]

A refractive error is an optical defect of the eye that prevents images from being brought to a sharp focus through cornea and lens onto the retina. Therefore, the image either focuses in front of retina or behind the retina and vision is blurred. Two refractive error conditions are common in children, myopia and hyperopia.

Myopia: Individuals with myopia are said to be "short-sighted" or "near-sighted" meaning they have good near vision but poor distance vision. With myopia the image is brought to focus in front of the retina, as the problem is a slightly elongated eyeball. It typically develops in childhood and usually progresses until adult growth is reached. At this point myopia rarely worsens.

Hyperopia: This is also known as "farsighted" vision, because persons with hyperopia have good distance vision but poor near vision. In hyperopia the eyeball is slightly short for the power of the lens and cornea. Most very young children are hyperopics, which is called physiological hyperopia. As they grow, the degree of hyperopia decreases. In adulthood, because of gradual loss of accommodation ability in the lens, there is eyestrain (discomfort) and decreased visual acuity. Both of these conditions are easily corrected with prescribed spectacles.

Extent of problem: It is estimated that about 5 percent of school children have some degree of refractive error. Usually children constitute 40% of total population. From available data, we expect that 20 million children to have some refractive error in India, and about 2000 to 4000 children per million population who require spectacles greater than 1 dioptor.

Management of refractive errors in children:

Refractive error must be corrected as early as possible. Usually it is bilateral, and if detected early and corrected properly it can prevent blindness in children due to amblyopia. It is very important to correct refractive error before six years of age. Often neither the child nor the caregivers are aware of this problem and the blindness occurs with no apparent symptoms. . Therefore, active screening is needed for every child in the community. In cases of uniocular errors, children may develop strabismus (squint) which also needs to be treated.

Refractive errors are associated with good vision and they require only correction with prescribed lenses and spectacles.

Management:

Refractive error needs to be managed using two basic principles:

1) Screening all children in the community for refractive error.
2) Making good quality spectacles available to children when and where they need them.

While taking up the first intervention of screening all children, programs must consider the following:

- What is the age group to screen? Older children are more co-operative and myopia is more common in 10+ years age group. However, myopia cal also appear in ages 0-10 and needs immediate correction.

- How often should a child would be screened? Usually this is done early and then repeatedly in school up to 13-14 years of age.
- What level of visual acuity is considered abnormal (less than 6/9, 6/12 or 6/18) and in need of evaluation by an eye specialist. It is essential that any screening program have an active referral process in place so that spectacles are permanently available to children at a cost families can afford.

To be successful in above areas, bringing awareness to the community about refractive error and simple treatment available would prove very effective. This involves educating caregivers, village health care workers, and children themselves on refractive error and on general eye care.

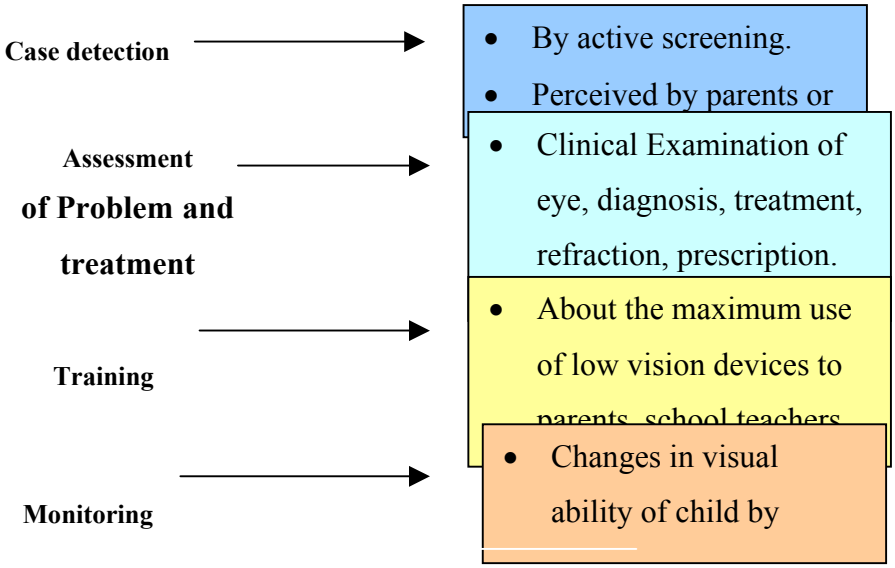
Low Vision

[NOTE: PHOTO MISSING. SD]

It is estimated that approximately 1 child out of 250 children are visually impaired as a result of eye disease. [NOTE; NEED TO CITE SOURCE. SD] Some of these children have near normal vision, some are totally blind, but the majority fall into a broad range between these two extremes. Children are said to have low vision or partial sight, when they have: a) A corrected visual acuity in better eye ranging from <6/18 to perception of light (PL) or b) a visual field of less than 10 degrees, and c) the ability to use their existing vision to perform tasks. These children are identified through the medical community, eye clinics, school for the blinds, integrated schools, school eye screening and community based rehabilitation programs. The purpose of low vision services is to maximize use of limited vision. Optical devices like hand or stand magnifiers, magnifiers mounted on spectacles or telescopes and closed circuit television for magnification of print all play an important role in achieving this. Altering the environment through greater contrast, better illumination, and increased image size also part of low vision services. Different studies report that these changes help fifty percent of children. [NOTE: CITE SOURCE. SD]

Sight is an important stimulus for child's development. The overall of education of the child, movement, socialization, cognition, employment, independence, and quality of life improve when the child is helped with low vision services. For the management of these children it is very important to receive co-operation of the child, his/her family, and eye care personnel. As shown below, the eye care personnel are mainly involved in the assessment of severity acuity, treatment and monitoring.

Different steps in management of children with low vision:



[NOTE: GRAPH UNCLEAR AND WORDS ARE DELETED. SD]

To determine the appropriate type of low vision aid, it is important to assess the child's personality, co-ordination, motivation and task undertaken. For example, the same magnification can be provided using different mounting systems and working distances.

There are many benefits in providing low vision aids to children with low vision, including

- Increase in visual stimulus, which helps in overall development of child,
- Increase in access to printed material (for education and private reading),
- Greater access to books, as children can use standard books instead of needing adapted large print books, which are often expensive and cumbersome.

But there are some limitations also of providing low vision aids to children with low vision, such as

- It makes child feel different from others, as the visual disability becomes more evident,
- Often the personnel and financial resources are not enough to provide the services needed, and
- Low cost, good quality magnifiers are not yet manufactured and made available in India. This problem can be solved by preparing +8D to + 28D magnifiers at low cost as it has been done in Nairobi, Kenya.

[NOTE: GIVE DETAILS. SD]

Other conditions responsible for Childhood Blindness

Glaucoma

Glaucoma is a condition of eye in which intraocular pressure exceeds the ability of the affected eye to tolerate it. The high intraocular pressure damages the optic nerve and retina, affecting vision. This usually occurs in both the eyes. The visual loss is irreversible. The glaucomatous optic nerve damage is similar in children and adults.

There are two types of congenital glaucoma in children:

1) Primary congenital glaucoma:

- Found in children in first two months of life but usually has developed within the first month of life,
- It is blinding if not treated immediately within the first years of life,
- It is result of an ocular development abnormality.

2) Secondary congenital Glaucoma: -

- Develops because of other health problems e.g., as a complication of congenital cataract surgery,
- Associated with cataract in children such as CRS
- Idiopathic.

Management:

Congenital Glaucoma is manageable but the visual loss is irreversible. We can stop further deterioration of vision by early diagnosis and treatment such as goniotomy for trabeculodysgenesis. In rural communities, families often have no access to tertiary care to treat glaucoma, a situation that needs to be improved. Visual rehabilitation with low vision aids after proper refraction is often helpful once the case is stabilized. Regular follow-up examinations involve assessment of vision, visual fields, measurement of intraocular pressure, and assessment of optic disc.

Retinoblastoma

(Child with retinoblastoma)

[NOTE: PHOTO MISSING. SD]

This disease occurs at the estimated rate of 1-3 cases per million population per year. The signs are leucocoria (white reflex in the eye) and proptosis. The usual treatment for unilateral cases is enucleation. Bilateral cases occur in 33% of cases of unilateral retinoblastoma. In order to improve the survival of these children, treat early, and avoid metastasis of the tumor, we need to increase awareness of the disease among all potential referral sources so that early diagnosis and referral to paediatric ophthalmic centers is ensured.

Opthalmia Neonaturum

[NO PICTURE. SD]

Ophthalmia neonaturum is purulent conjunctivitis occurring during the first four weeks of life. The common causative agents are neisseria gonorrhoeae and chlamydia trachomatis, the former being more a virulent strain. The symptoms are seen in the first three days of life, and if properly treated the eye remains normal. If the condition is not properly diagnosed and treatment is not available, the corneal epithelium is damaged and blindness usually results. Serious ocular complications develop in 30% of affected children and therefore, ophthalmia neonaturum is an ocular emergency. The disease occurs worldwide, including India in places where trained birth attendants do not conduct deliveries or antenatal/postnatal care are not properly developed. Ocular prophylaxis of newborns should become a common practice to prevent this condition.

Prevention and control of Ophthalmia Neonaturum:

The following steps should be undertaken:

- Antenatal Care: - Good antenatal care is necessary to screen and treat pregnant women with gonococcal infection.
- Neonatal Care: 1) Cleaning the lid margins immediately after birth. 2) Application of prophylactic medication with a) Tetracycline 1% eye ointment or b) Silver nitrate 1% eye drops.
- Early diagnosis and treatment with ceftriaxone 50 mg/kg body weight, IM injection as a single dose (maximum 125 mg) or Kanamyan 25 mg/kg body weight. IM injection as a single dose (maximum 75 mg).
- Surgical treatment for corneal opacification at the nearest paediatric ophthalmology center with this facility.

Teratogens

It is known that the embryo is susceptible to environmental influences that are relatively benign for the mature individual.

These cause severe malformation in the unborn child. For about 50% of childhood blindness the cause cannot be determined. In these children the abnormality is often present at birth, but there is no definite history of inherited disease. It is thought that in a significant proportion of these cases, various factors operate during intrauterine period which affect the development of eye. This results in loss of vision.

These are the few important known teratogens, which operate during early pregnancies in India, including rubella virus, syphilis infection, high doses of vitamin A, and ionizing radiation (exposure to x-rays).

These need to be prevented to reduce the blindness from unknown causes and for that we need to make people aware of these teratogens as well as continue research on specific risks..

Optic Nerve, Cortical Blindness, and Higher Visual Pathways

Optic nerve atrophy of genetic origin usually has autosomal dominant transmission. In India the schools for the blind surveys reported it to be present in about 6% of total admissions. The usual cause of blindness in children with optic nerve disease is infections of meninges of the brain, cerebral hypoxia at birth, head injuries in infancy, excess maternal alcohol consumption during pregnancy, or various abortifacents used in an attempt to end pregnancy. This blindness is often associated with other neurological disorders such as cerebral palsy. The visual prognosis in these children is stable.

Community intervention model

[NOTE: UNCLEAR HOW THIS FITS IT HERE. IS IT A PROPOSL OR IS THERE A MODEL IN PLACE? SD]

An ideal model for community intervention in childhood blindness has been developed. In India, it is felt that population of 6 lacs (600,000) should be the viable population for this kind of model to survive. The expected number of children would be 250,000 (40%), out of which 250 children would be expected to be blind from various causes. Half of these (125) children would be blind from untreatable causes which can referred to education and rehabilitation. The remaining would be blind from either preventable or treatable causes. It is estimated that 30% (40) would need to be managed surgically or medically at a paediatric ophthalmology treatment center. In addition to this there would be around 300 children in the community who would need treatment for refractive error.

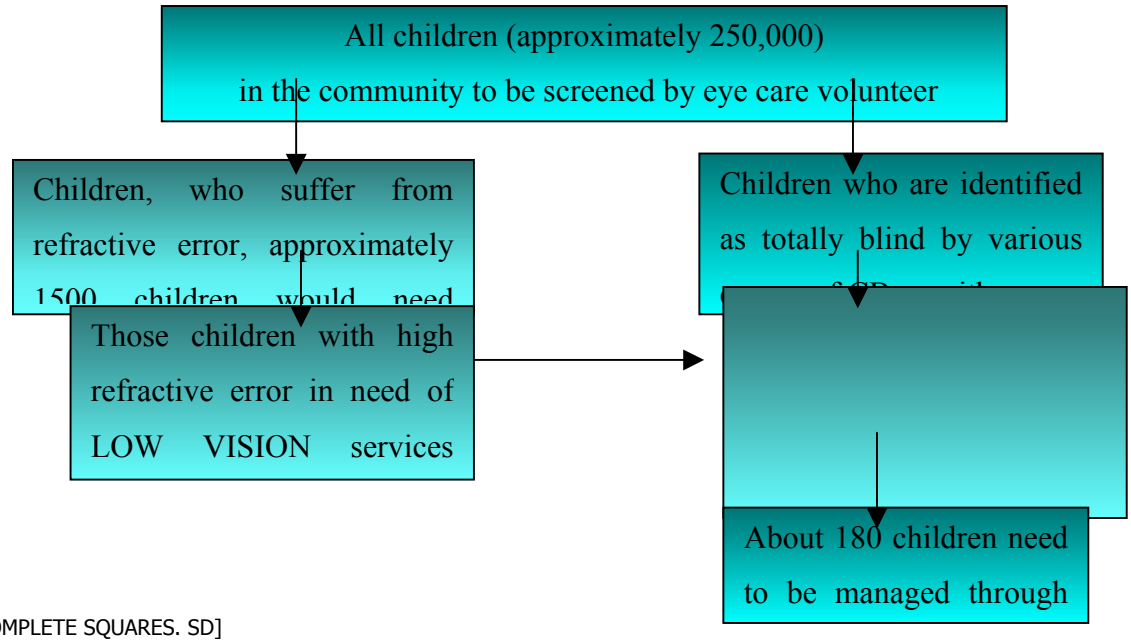
How to deal with it?

The aim of this model is to reduce childhood blindness in city with approximately 6 lacs population. To accomplish this, objectives need to be defined. Before the activities are begun the background information on the area should be collected to tell us about the overall structure of the community. The strategic plan towards achieving the above set aim is as follows:

Objectives:

1. To provide community intervention in form of early detection of cases of childhood blindness, refractive error, and low vision.
2. To refer the children from community level screening by volunteers to the peripheral units (one unit per 50,000 population) for refraction by a specialist.
3. To provide good quality spectacles to all those who need them at a cost they can afford.
4. To develop a paediatric ophthalmology treatment center attached to a routine eye care hospital in the area.

Diagrammatic representation of community intervention model: -



[NOTE: INCOMPLETE SQUARES. SD]

Different activities to be undertaken to achieve the above set of objectives:

The community should identify individuals to work as community eye care volunteers. After training, these volunteers would identify the children who are blind or visually impaired. The children who are blind would be directly referred to the paediatric ophthalmology treatment center. Those with refractive errors would be referred to one of the peripheral eye care units in a city where a person trained in refraction would examine these children. Those who have minor correction would be given proper spectacles. Those children with severe visual impairment would be sent to a tertiary paediatric ophthalmology treatment center. A paediatric ophthalmologist would examine these children and would do either surgical intervention or medical treatment followed by proper correction with spectacles. The complicated cases, which cannot be treated in this center, would subsequently be referred to the paediatric ophthalmology unit in the region.

Development of Paediatric Ophthalmology Treatment Center:

Once prevention and treatment is begun it is essential to develop the above-mentioned centers in the town with approximately 6 lacs population. Therefore, the compiling of the information will serve as a guideline for all interested groups in India (private hospitals, NGOs or government hospitals) planning to develop paediatric ophthalmology treatment centers beyond existing facilities. To enable all groups to find this information useful, the details of infrastructure, manpower and equipment is listed. The costs have also been calculated based on the market in India.

Various services at paediatric ophthalmology treatment center:

Surgical Treatment for: -

- Congenital cataracts in children
- Congenital glaucoma
- Retinopathy of prematurity
- Corneal scar correction – Keratoplasty
- Repair of strabismus (squints)

Medical Treatment for:

- Correction of refractive error
- Low vision services
- Long-term monitoring of children who have undergone above surgical treatment
- Follow up.

In planning peadiatric services, it is important to understand that child's eye is not exactly a smaller form of adult eye, but that it reacts in different way to treatment; therefore the benefit of setting up paediatric ophthalmology units is to provide best eye care to children for whom service needs are unique. Eye care in children is different in that children cannot report vision problems and do not co-operate as adults. Therefore, a different clinical approach is needed. Peadiatric ophthalmology needs long term commitment and specialized skill development.

Resources at paediatric ophthalmology center:

These are the basic minimum needed to begin the center. More staff would be added as the quantity of work and skills improved.

Staff at paediatric ophthalmology Treatment Center: -

1 Paediatric Ophthalmologist
1 Anaesthetist Nurse
1 Ophthalmic Nurse
1 Refractionist
1 Low vision Person
1 Paediatric Nurse
1 Operating Room Assistant

Space: - The center is proposed as an annex to a routine eye care hospital. An extension of approximately 2000 square feet would be essential. The cost of infrastructure in the town would range from Rs. 200,000 to Rs. 400,000 inclusive of fittings and furniture.

The outpatient department would consist of waiting room for patients and their families, consultant's room, refraction room, and treatment room. The inpatient department includes wards with a ten bed capacity (child and caregiver) and nurses' room. The surgery department consists of premedication room, operation room, recovery room, and storage (for drugs and anesthesia equipment). The equipment which are essential for this unit would cost around Rs. 800,000. These include vision testing charts, prism bars, an ophthalmoscope, a slit lamp (preferably portable), a Hess chart, a hand-held application tonometer, and toys at a cost of about Rs. 200,000. In the operating room the full set for paediatric anesthesia which includes Boyle's apparatus, halothane vaporizer, pulse oximeter, paediatric gas mask, paediatric endotracheal tubes, and suction apparatus would cost about Rs. 500,000. The operating microscope will cost Rs. 250,000, surgical instrument Rs. 30,000, and equipment for lensectomy Rs. 60,000. The total cost for equipment should be about Rs. 900,000. Hence, the total cost should be approximately Rs. 1,400, 000. The running cost of the center, including salary of the staff, consumables, and medication would be about Rs. 600,000 per year.

Activities related to primary health care:

These activities are routinely carried out by health personnel in programs for maternal and child health. There is a need to reorient them to include more emphasis on prevention and control of childhood blindness. The following activities need to be strengthened:

1. Ensuring the adequate supply of vitamin A to women's in the childbearing age group and to children through diet which are the most crucial measures to avoid blindness because of vitamin A deficiency.
2. To bring awareness about food and nutrition, feeding practices of children, advantages of breast-feeding, and avoiding use of harmful traditional eye medicines which would reduce corneal scars.
3. Measles, rubella immunization.
4. Diarrhoea control by safe water and proper sanitation measures.
5. Provision of appropriate drugs and for prevention and treatment of minor problem of the eye.
6. Early identification and referral of potentially blinding conditions and referring them at proper time.

It is clear that the accomplishment of the above six steps can only be accomplished through partnering with other NGOs and government efforts working in maternal and child health, sanitation, farming, nutrition, epidemiology, and health education. This

partnering can establish a model of cooperative working relationships for other ORBIS programs in India as well as in other countries.

Community Based Rehabilitation

Community Based Rehabilitation (CBR) is an extension of the term "Rehabilitation", where the person is rehabilitated within his or her community with active family and community participation. Basic principles include teaching culturally appropriate functional skills in the natural environment. It is a comprehensive package of interventions consisting of **prevention, treatment** and **rehabilitation, which** the community itself provides. **Transfer of skills** is the essence of community based rehabilitation, bridging the gap between the need and the service provision and also making **rehabilitation** more **cost effective.** It is a program, which ensures awareness and empowerment of the community so that the whole process becomes sustainable. The various components of Community Based Rehabilitation program are 1. Developmental Intervention for children (0-5 years age group) 2. Integrated education 2. Medical/Surgical treatment, and, 4. Functional, social and economic rehabilitation. economic rehabilitation.

Appropriate Technology Development

There is an increased need to provide information on modern therapeutic equipment and proper use, to introduce telemedicine, to improve on surgical and management skills, to ensure availability of low cost quality spectacles, and to share information and experiences of other developing countries where low cost technology is developed and efficiently used. Such model programs exist, such as in Nairobi, Kenya where low vision aids are produced locally at very minimum cost. There is also a need to facilitate technology transfer by producing and disseminating audio-visual and written material in India on problems of childhood blindness. Using local production of material to reduce cost. Using local supplies, materials are dependable and no time is lost in procurement of supply.

Advocacy in Childhood Blindness

There is a need for development of health education material in eye care for children, to be distributed at all levels. The beneficiaries are the general population, families, children in different age groups, school teachers, technical staff involved in eye care, and other allied medical specialties such as paediatrics, obstretics, neonatology, and village health care workers. The information would vary depending upon on the audience and subject. Different advocacy kits can be developed on childhood blindness and distributed. The different activities undertaken would include

1) To create advocacy and public awareness on child visual health at a broad social and government level,
2) Dissemination of information for the general population in the community regarding screening of eyes and availability of spectacles in the community.
3) Develop and circulate training material on retinopathy of prematurity in audio-visual tapes, slides, and written material for ophthalmologists, paediatricians, obsteticians and general practitioners.
4) To create slides and written material related to high corneal retrieval program and distribute it to all eye banks in India.
5) To prepare preventive and educational materials in many media including picture format to instruct varied groups regardless of literacy level or language spoken
6) To partner with NGOs doing all related work on child health, safety, nutrition, and survival to support their efforts and imbed childhood blindness strategies into existing programs
7) To identify patterns of health information transfer in rural areas to use existing communication systems to assure early and appropriate referrals for childhood blindness cases.

Capacity Building in Paediatric Ophthalmology

There is a need to develop unique paediatric ophthalmology treatment centers as a part of eye care hospitals. For these centers sufficient human resources is essential. Without addressing this, it will be extremely difficult to run these centers effectively. Such capacity building encompasses much more than simply training those involved in management of childhood blindness; it includes motivating, training, equipping, supporting and developing the personnel at many levels of service. There are three cadres of eye care workers, which need to be addressed here, including

- Paediatric ophthalmologist
- Refractionists
- Low vision service providers
- Community eye care volunteers
- Surgical and clinical nurses
- Biomedical staff
- Workers to serve as liaisons to families

1) Paediatric Ophthalmologist

These will be selected for their interest in acquiring the skills in paediatric ophthalmology and committing to continued practice and training others. These people will have knowledge of eyes and vision of children as well as acquired skills to treat the various conditions of childhood blindness. They may be mainly operating in the field of routine adult ophthalmology but have special interest in paediatric ophthalmology. There are a few centers in India like Aravind Eye Hospital in Madurai, which would be identified as paediatric ophthalmology training centers for the proposed training.

2) Refractionist-

These would be the people who have undergone training in identification of refractive errors and prescription of glasses. Those doing the work of refraction in adults would be oriented in doing the same in children. This can also be done in the training centers for Paediatric Ophthalmology.

Low Vision Service Providers-

This group needs to be developed, as very few are currently available. The task involves refraction, prescription of low vision devices, training in use of the low vision aids, adapting the environment for low vision accessibility, use of adapted materials for everyday use, and treatment of amblyopia in conjunction with an ophthalmologist.

Community Eye Care Volunteers-

These should be individuals identified by the community based on their interest in social service to be trained for the early identification and referral of blinding conditions in children. They should also be trained to screen the children with any eye problem as well as screening of all children in the community. Their emphasis should be on early referral of cases to proper levels of eye care.

Surgical and Clinical Nurses-

These staff members provide valuable support to all medical procedures in both inpatient and outpatient settings. The rigorous training of nurses in childhood blindness can alleviate the doctors of routine care and assure the smooth functioning of each procedure.

Biomedical Staff-

Often equipment is donated or purchased, then it cannot be repaired when it fails to work properly. By including the biomedical staff in all planning, and securing proper training for them, services are assured of having calibrated, regulated, and well monitored equipment as well as timely repairs if they break down.

Family Liaisons-

Both families and medical personnel benefit by having someone to guide families through the process of securing paediatric care, answering routine questions, reminding them of appointments, and updating them of their child's status. Families tend to find this person very reassuring, which increases their compliance with medical directions and follow-up.

[SUMMARY STATEMENT NEEDED, PROJECTIONS OF SPECIFIC NEXT STEPS. SD]