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ORBIS 20 YEARS IN INDIA

GAME CHANGERS Ipsos

Status of Child Eye Health in India

A Comprehensive Report

Contents

Foreword

India is the second-most populous country in the world and home to over 20 per cent of the world's blind population. Unfortunately, India is also home to the largest number of blind children in any one country. Since children constitute only three per cent of the world's blind population, childhood blindness has not been given its due importance as compared to other causes of blindness and visual impairment. However, if childhood blindness is measured in blind-person-years, it is second only to cataract blindness.

When Orbis started its journey in India in 2000, child eye care was not one of the focus areas of ophthalmology fraternity in the country. There were only four comprehensive tertiary paediatric eye care centres in India in 2000. Over the last 20 years, one of key achievements of Orbis is establishing pediatric ophthalmology as a distinct sub speciality in the ophthalmic landscape, thereby making sure that children across India have access to quality care for generations to come. Through our work across the country, Orbis has not just been helping eye hospitals create child friendly spaces and infrastructure, but also assuring quality service delivery and training the ophthalmology teams in pediatric eyecare.

Today, we have created a network of 33 Children's Eye Centers (CECs) across 17 States, which is the largest network of children's eye care in any one country. The report has detailed out the Orbis CEC model in India for replication and scaling-up. Three of the existing tertiary-level paediatric facilities in the country were developed as Pediatric Ophthalmology Learning and Training Centres (POLTCs) by providing infrastructure as well as technical support. We are helping our partner hospitals expand their community outreach through school and *Anganwadi* screenings, reaching out to more than 17.5 million children across the country.

The space of pediatric ophthalmology has changed ever since we began our journey 20 years back. One of the key objectives of this Report, as Orbis completes 20 years in India, is to showcase this transformation and do a reality check of the current status of child eye health in India, understand the ongoing development programs, share some of our learnings and innovative models that helped us make a difference, and discuss on the way forward, including that during the New Normal.

The Status of Child Eye Health in India includes systematic review of literature on child eye health in India. It also comprises of primary research in the form of in-depth interviews with doctors, ophthalmologist who are subject matter experts on different eye conditions.

When uncertain times strike, innovative models and approaches are imperative to ensure quality eye care for all. The Report also touches upon the impact of COVID-19 on children's eye care, eye hospitals and more.

Finally, this Report aims to serve public health professionals, primary healthcare providers, early childcare providers, policy makers, community and business leaders, community-based organizations, educators, and others interested in improving the health of children, with special focus on eye care. As we keep the discussions open with this Report, we hope it inspires effective collaborations, innovative approaches and sustainable solutions to Change the Way World Sees. Together, we can ensure that every child receives accessible and affordable eye care services across the country.

RISHI RAJ BORAH
Country Director, Orbis India

Preface

Childhood blindness accounts for four to five per cent of all blindness in the world. While there are programmes and initiatives addressing the child eye health, early detection, prevention, and promotion, there is an urgent need to step up the initiatives, scale up programmes across the length and breadth of our country and making eye care accessible, available, and affordable.

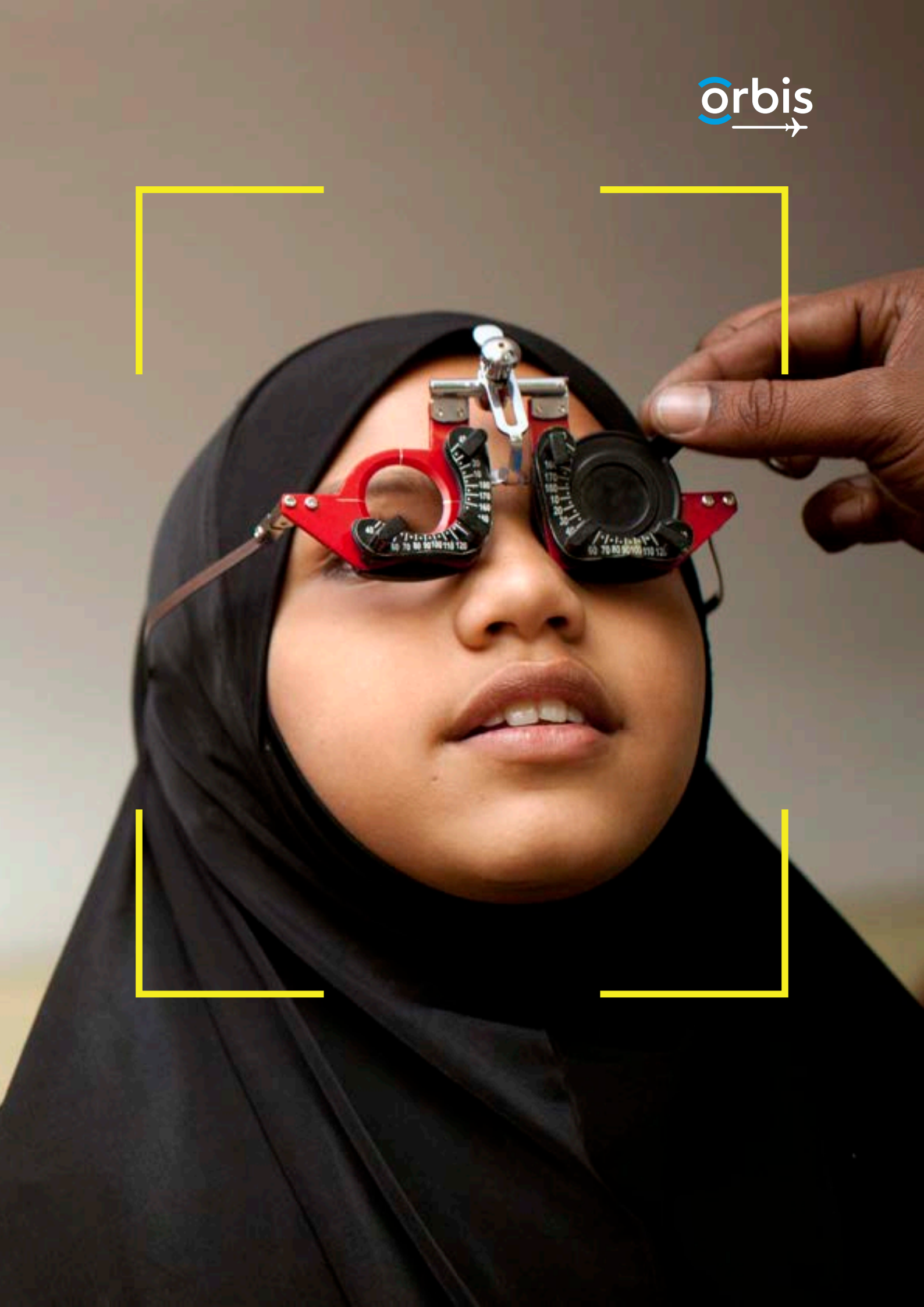
The needs of visually impaired children are different from visually impaired adults, both in terms of diagnosis and treatment. Therefore, there is a need to develop and strengthen skills for providing eye care to children. The needs relate both to infrastructure and available human resources. In parallel there is a need for wider awareness among parents about the different symptoms, what are the signs that call for attention, and where to seek care. This awareness combined with strengthening infrastructure, human resource are essential pre requisites to make child eye care accessible and available.

For delivery of Pediatric eye care a synergy at primary, secondary and tertiary levels of eye care is necessary with a clear and strong referral linkages to provide full continuum of care and treatment. Data in form of facts, numbers, and what works are essential ingredients for driving policies and scaling initiatives. There are very few studies in India to estimate the prevalence of childhood blindness, discuss impact of weal eye care infrastructure of children, or what we have learnt about what has worked as successful models of prevention, care, or promotion.

At Ipsos our focus is to present research in form that aids decision making and strengthen development programmes. We thank Orbis India team to choose us as their partner for this very relevant and timely publication of this comprehensive report on child eye health in India. The report is a comprehensive compilation of different eye health conditions, magnitude, causes and available treatment options. It further provides an overview of programmes across India that are addressing the issue of child eye healthcare.

This report thus aims to serve public health professionals, primary healthcare providers, early childcare providers, policy makers, community and business leaders, community-based organizations, educators, and others interested in improving the health of children in general with special focus on eye care. We hope that the information on existing approaches and intervention including recommendations by leading experts, lay out the road map for a comprehensive service model integrated within primary healthcare delivery that prevents avoidable childhood blindness for millions of our children.

TRIPTI SHARMA
Research Director, Ipsos Public Affairs



Acknowledgement

Ipsos and Orbis would like to take this opportunity to express their gratitude to everyone who has contributed to the development of this report, shared their thoughts, expressed their views, and provided valuable feedback which has helped us to come up with the report. First, we would like to thank all the experts and the partner doctors who were interviewed as part of the primary research. Their time and valuable feedback on the subject are sincerely acknowledged. Mentioned below are the names of experts in eye care and ophthalmology who have contributed to the study.

Subject Matter Expert Group

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This report focusses not only on eye conditions from a clinical perspective but the ways in which it impinges upon the lives of children, their family members, the larger community, society and the nation. We hope that this report would be a concrete step towards a comprehensive understanding of contemporary status of child eye health in India. We hope that it would be read and referred to by people from all walks of life. We anticipate that the findings would add to the existing knowledge about the child eye health in India, the challenges and the solutions that are currently available and that it leads all relevant stakeholders to pay as much attention to the subject as it deserves.

Abbreviation

AIIMS : All India Institute of Medical Sciences

AMD : Age-related Macular Degeneration

ASHA : Accredited Social Health Activist

AWW : *Anganwadi* Worker

GNI : Gross National Income

IAPB : International Agency for Prevention of Blindness

LVPEI : L V Prasad Eye Institute

MDG : Millennium Development Goal

NICU : Neonatal Intensive Care Unit

NPCB : The National Program for Control of Blindness

NRHM : National Rural Health Mission

OPD : Out Patient Department

PHC : Primary Health Centers

QALY : Quality of Adjusted Life Years

Rb : Retinoblastoma Protein

REACH : Refractive Error Among Children

ROP : Retinopathy of Prematurity

WHO : World Health Organization

About the Document

The World Health Organization report[1] estimates that globally, at least 2.2 billion people have a vision impairment, and of these, at least 1 billion people have a vision impairment that could have been prevented or is yet to be addressed. Vision impairment occurs when an eye condition affects the visual system and one or more of its vision functions. The burden of vision impairment tends to be greater in low and middle-income countries and among underserved populations, such as women, migrants, indigenous peoples, persons with certain kinds of disability and those living in rural areas. Population growth and ageing, along with behavioural and lifestyle changes, and urbanization, would increase the number of people with eye conditions, vision impairment and blindness in the coming decades.[2]

Healthy vision influences the overall development and quality of life of the individual and his/her interactions with the society. Visual impairment can affect employability, increase dependency and may cause social and cultural isolation. Eye health is very important when it comes to children, and childhood vision disorders may continue to affect health and well-being throughout the individual's adult years. Young children with early onset of severe impairment can experience delayed motor, language, emotional, social, and cognitive development with lifelong consequences. School-going children with vision impairment can experience lower levels of educational achievement and self-esteem than their normally sighted peers.

India is responsible for about one-fifth of the global burden of blindness and also accounts for a very high proportion of visually impaired people in the South Asian region.

India alone is responsible for about one-fifth of the global burden and also accounts for a very high proportion of visually impaired people in the South Asian region. India is home to 407 million children below the age of 16 years. This accounts for 40% of the Indian population. Although there is no nation-wide survey conducted in India on the prevalence of eye health issues and blindness among children, an estimated 0.8 in 1000 children between 0-15 years are blind in India (Grover & Arora, 2012).

Control of childhood blindness is one of the priorities identified for achieving the goals of Vision 2020 - the program launched by the World Health Organization (WHO) for the elimination of avoidable blindness. This is considered a priority because "blind-years" (number of years that a blind person lives after going blind) due to childhood blindness in half of the children is avoidable (treatable/preventable). Regular eye healthcare can enable early detection and possible prevention of avoidable vision

1 World Health Organization (2019) World report on vision
2 World Health Organization (2019) World report on vision, page xi

related problems, and provides the person affected with the promise of a more fulfilling life. While there has been an increase in making social infrastructure inclusive and disabled friendly, it is still insufficient.

An integrated, comprehensive status report on child eye health in India by Orbis and Ipsos.

This report is an integrated, comprehensive status report on child eye health in India. It consists of a systematic review of literature on child eye health in India. It also comprises of primary research in the form of in-depth interviews with different experts on various aspects of eye health and eye healthcare. The list of experts is provided at the end of the document as Annexure 2. The review of literature is from various national and international research, policy and working papers. They revolve around various aspects of child eye health such as magnitude and nature of eye health conditions, aspects of care, treatment, importance of eye health, and the prevailing models of eye health for children. It hopes to engage with public health professionals, primary healthcare providers, early childcare providers, policy makers, community and business leaders, community-based organizations, educators, and others interested in improving the health of children in general, with special focus on eye care.

The document is classified into six sections with specific purposes as enumerated under:

Magnitude of the Problem

This section focusses on the affected children vis-à-vis larger population in the age group of those below 16 years from a global as well as an Indian perspective. It lends special focus on the aspects of awareness amongst parents about potential threats of childhood disorders and their long-term effects. It also provides insights about access to testing facilities and possible treatment opportunities available, and an overall analysis of status of eye healthcare.

Importance of Child Eye Care

This section explicitly deals with the economic impact of visual impairment on an individual, and on the society at large. This section emphasizes the necessity to identify, treat & eliminate disorders thus eliminating blindness at a later stage considering the economic burden of the latter being far more exhaustive than early detection and rectification.

Causes and Conditions

Root cause analysis of commonly identifiable disorders through basic analysis of prevalent eye-conditions in children. A special effort is made to earmark avoidable blindness and the regional variations in prevalence and causes of eye problems.

Existing Models of Care

This section analyses the various existing models of child eye care in India, based on the multi-sectoral engagement involved, and the requirement of capacity building of pediatric ophthalmologists. Special focus is laid on aspects of prevention, treatment and rehabilitation. The importance of eye care related promotional activities, maternal health and the screening of new-borns for detection of vision related anomalies are detailed. The section also covers social protection of the visually impaired, and social integration methodologies objectively analysed, with prominence on education for the visually impaired.

The Orbis Child Eye Healthcare Model

A model designed for effective child healthcare from an Indian perspective is examined as an effective bridge between the existing gaps in child eye healthcare, and which scales the barriers affecting availability, accessibility, acceptability and affordability of child eye care in India.

Way Forward with Recommendations by the Experts

This section proposes an approach for universal coverage of child eye healthcare with specific suggestions for improving it in India. The impact of the outbreak of the COVID-19 pandemic, and revelations of shortcomings of Indian eye healthcare systems has also been factored in.

Chapter 1

Magnitude of The Problem

The impact of blindness and vision impairment on individuals, their families, communities and countries is considerable. Visually impaired people may find it difficult to work, access education, and lead independent, fulfilled lives. Vision assumes a significant role in children's physical, psychological, and social development. Being able to see clearly is important for a child's overall development and helps the child discover and learn about the world. Children who are blind must overcome a lifetime of emotional, social and economic difficulties that affect not just them, but their families and society as a whole. Uncorrected vision issues can impede children's development, meddle with learning, and even lead to perpetual vision misfortune; early recognition and treatment therefore, are basic.

The above issues can be addressed through adequate intervention. Bringing in a difference to the above scenario, we need to understand the scale of child eye health issues and its causes. Towards this end, an understanding of the issue's magnitude from a global perspective in general and the Indian scenario in particular, is the logical first step.

This section discusses the extent of various eye health issues among children across the world and provides insights into the nature and extent of eye health problems among children in India. Further, it describes the state of eye healthcare providers in developing countries like India.

1.1 Eye Health Issues Among Children

According to the WHO, childhood eye health issues is a group of diseases and conditions occurring in childhood or early adolescence which, if untreated, may result in blindness or severe visual impairment. Some of the conditions commonly observed are:

- CATARACTS FROM RUBELLA
- RETINOPATHY OF PREMATURITY (RoP) FROM PREMATURE BIRTH
- STRABISMUS
- CORNEAL SCARRING FROM MEASLES, VITAMIN-A DEFICIENCIES, OR TRADITIONAL MEDICINES

The below list indicates specific eye problems in children, their description and available treatment

Astigmatism

An irregularly shaped cornea that can cause blurred vision.

Glasses if it causes blurred vision.

Droopy Eyelids
(Ptosis)

When the eyelids are not as open as they should be. This is caused by weakness in the muscle that opens the eyelid.

If severe, it can cause poor vision development (amblyopia) and need eyelid surgery.

Swollen Eyelids
(Blepharitis)

An inflammation in the oily glands of the eyelid. This usually results in swollen eyelids and excessive crusting of the eyelashes.

Warm compresses and washing the eyelids with baby shampoo. Antibiotics may be needed if there's an infection.

Scratched Cornea
(Corneal Abrasion)

A scratch of the front surface of the eye (the cornea). It can be very painful, and the eyes usually tear and are also sensitive to light.

Antibiotic drops or ointment to promote healing and prevent infection.

Stye
(Hordeolum)

A painful, red bump on the eyelid due to an infected oil or sweat gland.

Warm compresses and antibiotic drops or ointment.

Falsely Misaligned Eyes (Pseudostrabismus)

Caused by a wide nasal bridge or extra folds of skin between the nose and eye—hence, the eyes only appear cross-eyed.

None. The eyes should be monitored to be sure they remain healthy.

Glaucoma

A condition in which the pressure inside the eye is too high. If left untreated, glaucoma can cause blindness. Warning signs are extreme sensitivity to light, tearing, persistent pain, an enlarged eye, cloudy cornea, and lid spasm.

Glaucoma in childhood usually needs surgery.

Lazy Eye
(Amblyopia)

Reduced vision from lack of use in an otherwise normal eye. It's often caused by poor focusing or misaligned eyes.

Applying a patch or special eyedrops to the "good" eye. Other treatments commonly include glasses or eye muscle surgery for misaligned eyes.

Cataract

A clouding of the lens of the eye.

Most cataracts must be surgically removed. Cataracts in babies and children are rare and usually not related to cataracts in adults.

Farsightedness
(Hyperopia)

Difficulty seeing close objects. A small degree of farsightedness is normal in babies and children.

If it becomes severe or causes the eyes to cross, glasses are needed.

Nearsightedness
(Myopia)

Difficulty seeing faraway objects. Nearsightedness is very rare in babies but becomes more common in school-aged children.

Glasses are used to correct blurred distance vision. Once nearsighted, children do not usually outgrow the condition and contact lenses may be worn when old enough.

Misaligned Eyes
(Strabismus)

When one eye turns inward, upward, downward, or outward. This is caused by eye muscles that do not work well together.

Glasses, patches, or surgery depending on cause for the misalignment.

Chalazion

A firm, painless bump on the eyelid due to a blocked oil gland.

May resolve on its own or be treated with eyedrops or warm compresses. In some cases, minor surgery may be needed.

Blocked Tear Ducts

In some babies, the eyes overflow with tears and collect mucus.

Gentle massage of the tear duct can help relieve the blockage. If that doesn't work, a tear duct probing procedure or surgery may be needed.

Red Eye
(Conjunctivitis)

A reddening of the white part of the eye, usually due to infections, allergies, or irritation. Signs include tearing, discharge, and the feeling that there's something in the eye.

Depending on its cause, red eye is often treated with eyedrops or ointment. Frequent hand washing can limit the spread of eye infections to family members & classmates.

Source: Your Child's Eyes (2011 American Academy of Pediatrics, Updated 05/2016)

The magnitude of eye health issues among children varies across different regions, and is broadly dependent on socio-economic conditions, and availability of primary healthcare and eye care services (Gilbert at al., 2006).

1.2 Global Estimates of Visual Impairment

WHO[3] estimates 2.2 billion people globally to have a vision impairment or blindness. This figure takes into consideration those with near vision impairment due to presbyopia (1.8 billion), moderate to severe distance vision impairment or blindness due to unaddressed refractive error (123.7 million, e.g. myopia or hypermetropia), cataract (65.2 million), age-related macular degeneration (10.4 million), glaucoma (6.9 million), corneal opacities (4.2 million), diabetic retinopathy (3 million), trachoma (2 million) and other causes (37.1 million).

There are an estimated 91 million visually impaired persons in the entire South East Asia region, with almost one third of the global share– 12 million with blindness and 79 million with low vision. India alone is responsible for approximately one fifth of the global burden, and houses the maximum number of visually impaired adults in the region. The population of the countries varies from a low of 329,000 in Maldives to a high of 1.12 billion in India (Murthy and Vashist, 2013).

African population-based studies, mostly utilizing key informants, have suggested that the prevalence of blindness in children is likely to range between 0.2/1000 children and 0.8/1000 children. With significant reductions in the prevalence of vitamin A deficiency related

3 World Health Organization (2019) World report on vision

blindness, the magnitude of childhood blindness in sub-Saharan Africa has reduced from the previous estimate of 1/1000 children. In recent surveys of schools for the blind in Africa, the proportion of children blind due to cataract, ranges between 13% and 26% (Courtright, 2012).

Socio-economic development (as measured by under-five mortality rates) has been correlated with the prevalence of childhood blindness. Globally, congenital cataract has been estimated to account for around 15–20% of all blindness in children. This estimate was made at a point in time when the global estimate of childhood blindness in developing countries was at 1/1000 children.

1.3 Magnitude of Eye Health Issues among Children in India

As reported by Family Health and Development Research Service Foundation (2007), India houses the highest percentage of population affected by cataract in the world, as well as high cataract prevalence rate. Singh et al. (2017) mentions that childhood blindness is found to be the second largest cause of blindness following cataract.

Despite it being the second largest cause of blindness, the prevalence of blindness in children is known to be low, at around 0.8/1000 currently. The prevalence is determined by the methodology used to determine blindness.[4] Usually, large population-based surveys are used to estimate blindness. Such surveys are few. A larger sample size of children is required to provide accurate data on the prevalence and causes of childhood blindness.

Chiefly, corneal and lenticular conditions are found to be causes of blindness among children. However, refractive errors are major issues among children outside blind schools. Within that, Myopia[5] is the major eye health issue affecting children across the globe as well as in India. In India, the population-level surveys that have examined prevalence of childhood blindness, have estimated the prevalence ranging between 1.06/1000 (using VA <3/60) to 1.7/1000 (using VA <6/60). Gudlavalleti and Venkata (2017) points out that estimates of prevalence grossly underestimate the extent of the true incidence of childhood blindness.

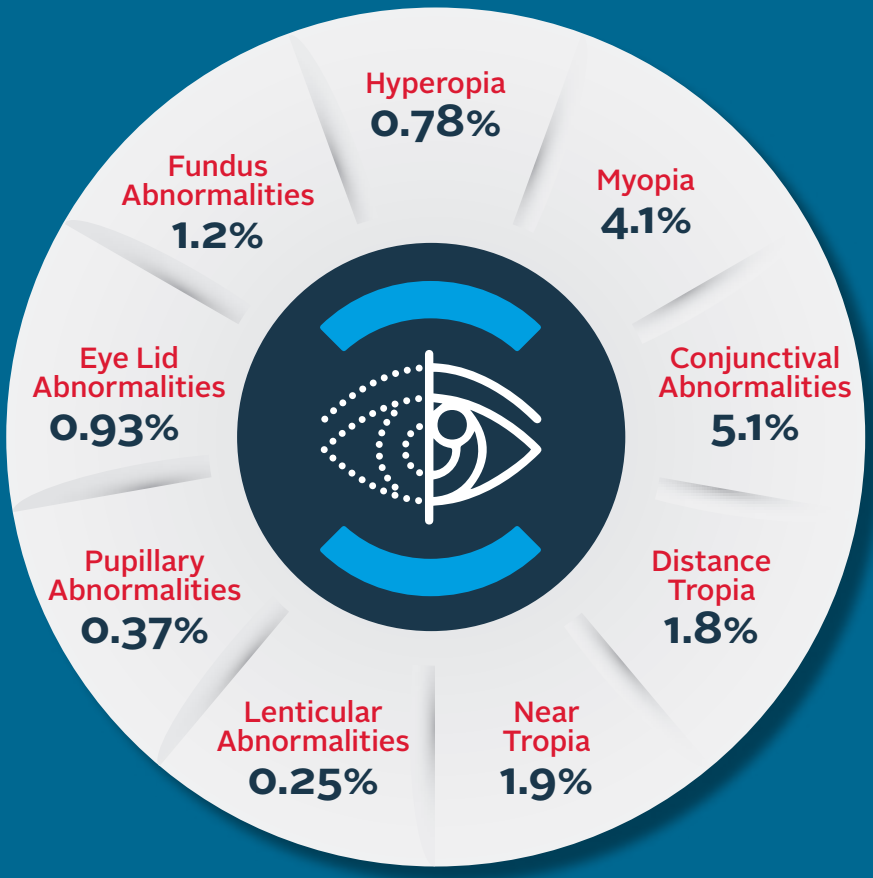
Refractive errors are major issues among children outside blind schools. Within that, Myopia5 is the major eye health issue affecting children across the globe as well as in India.

However, a few important surveys conducted in various states in India that serve as a guiding factor in appreciating the prevalent situation nationwide are submitted below:

- Another study among urban and rural school going children in west Uttar Pradesh involving 4838 children between 5 to 15 years found a prevalence of Ocular morbidity among 28.65% of urban children and 30.05% rural children. Overall incidence of visual impairment was 4.9/1000 children (Singh et al., 2017).

4 Wadhwani M, Vashist P, Singh SS, Gupta V, Gupta N, Saxena R. (2020). Prevalence and causes of childhood blindness in India: A systematic review. Indian J Ophthalmology; 68:311-5

5 Myopia is a condition in which close objects appear clearly, but far ones don't.



NATURE OF ANOMALY

A population-based study conducted by Dandona et al. (2002) covering 4414 children between 7 to 15 years in rural Andhra Pradesh revealed the following prevalence pattern

- A study in Tumkur district of Karnataka (Kemmanu et al., 2018) highlighted 6.54% children as having Ocular Morbidity. The studies both in Uttar Pradesh as well as Karnataka revealed refractive errors as major cause of ocular abnormalities.

- Sing, K. N., James, M. R., Yadav, A., Kumar, R., Asthana, S., & Labani, S. (2019) found prevalence of myopia on an average 21.1% children, in a study on students from classes 1 to 10, aged 5 to 15 years in two private schools in Gurugram, Haryana. Another interesting factor noted was the higher prevalence among boys than girls (25 vs. 19%). This could be an attribute of the socioeconomic conditions, gender inequity in school enrolment of the particular society/State where the study was conducted.

- A Longitudinal study on Incidence and progression of myopia and associated factors in urban school children in Delhi found that unlike in previous researches, the incidence of myopia is much higher than reported. The results showed a statistically significant higher incidence within younger ages. The incidence increased by 8-9 years of age and remained high till around 12 years after which a decrease was observed (Saxena R, Vashist P, Tandon R, Pandey RM, Bhardawaj A, Gupta V, et al., 2017).

- V. Kemmanu et al. (2018) in a population based cross sectional survey of children ≤15 years in Pavagada and Madhugiri Taluks of Tumkur district in Karnataka found that the

prevalence of Childhood Ocular Morbidity (COM) was 6.54%. Refractive errors (2.77%) constituted the major cause of COM. The prevalence of blindness (best corrected visual acuity of <3/60 in the better eye) was 0.09%. Whole-globe anomalies (25%) and uveal coloboma (25%) constituted the main causes of blindness.

Rural areas have more instances of corneal problems and cases of corneal scarring (Kerato Malasia). Some of these children have had episodes of diarrhea or measles or vitamin A deficiency prior to that. These episodes led to corneal melting and corneal scarring, which leads to corneal blindness. In areas like Uttar Pradesh there are children who have not been treated on time and have been left in blind schools.

Retinopathy of Prematurity (RoP) is another major disorder and is primarily a disease of the retina and blood vessels. The percentage of premature children have increased with In-Vitro Fertilizations (IVF). The intra-uterine growth retardation of children has increased which has increased the incidence of RoP. In case of premature births, when the blood vessels are not fully developed they are more prone to vascular anomalies which lead to RoP. Abnormal blood vessels may grow in the peripheral part of the retina and may lead to a retinal detachment and ultimately permanent blindness. It often happens that gynecologists and physicians are focused more on the overall health of

In India, prevalence of glaucoma is high - almost 4.0 to 4.5% of the population.

the premature babies than their eye condition and may not be fully aware about this condition.

In India, prevalence of glaucoma is high - almost 4.0 to 4.5% of the population. Though prevalence of pediatric glaucoma is not substantial, it is very significant as it may lead to blindness if not treated on time. Children may also be born with congenital cataract, congenital glaucoma or RoP. Over time, children may sometimes develop refractive errors or a squint, which, if not corrected, can lead to amblyopia. Causes of childhood blindness in poor countries are mainly related to Vitamin A deficiency leading to corneal blindness. If the mother has problems during pregnancy, the incidence of genetic diseases such as rubella, are more common. Prevalence of pediatric and developmental glaucoma is not that high, though the rates in South India are more than those of western countries. It is 1 in 3300 in Andhra Pradesh as against 1 in 10000 in western countries which accounts for 4.2% of all childhood blindness. It may be attributed to consanguinity in marriage which is relatively common in this part of the country.

Thus it can be concluded that visual impairment exists among children, irrespective of geographical locations and urban-rural diversity. Lack of awareness, aided with insignificant testing of prevailing ailments result in prevalence of childhood anomalies. This is revealed only when tested with a focused approach on child eye care on any targeted group. All the studies unanimously establish that ailments like Retinopathy of Prematurity (RoP) (RoP), pediatric glaucoma, instances of Cornea problems, Childhood Ocular Morbidity (COM) exist unnoticed in India and can only be unearthed through a focused approach to testing.

NATIONWIDE PREVALENCE A SNAPSHOT

OCULAR MORBIDITY

30.05%
OCULAR MORBIDITY AMONG RURAL CHILDREN IN UTTAR PRADESH

6.54%
OCULAR MORBIDITY AMONG RURAL CHILDREN IN KARNATAKA

PREVALENCE OF MYOPIA

ON AN AVERAGE
21.1%
CHILDREN WITH PREVALENCE OF MYOPIA

CAUSE OF BLINDNESS

25%
UVEAL COLOBOMA

25%
WHOLE-GLOBE ANOMALIES

1.4 Barriers to Eye Healthcare: Lack of Access and Awareness

Childhood blindness has a significant impact on children's health, education and quality of life. The loss of income and productivity associated with a lifetime of blindness are costly to individual children, their families and the country (Borrel et al., 2010). While most causes of blindness are treatable and preventable, there is huge gap in availability and accessibility of care for child eye health in developing countries.

In India, several studies mention the inadequacy of service availability for children's eye care. On the one hand, there is no nationwide data available to know the prevalence of eye diseases among children. On the other hand, gaps in awareness and availability of eye care adds to the severity. Further, the studies on community awareness on eye health are mainly done in southern India alone. Some of them are detailed.

- A study by Sethilkumar et al. (2013) in Chennai revealed that parents were aware of common eyesight issues like refractive error and squint, but lacked awareness of amblyopia.[6] There was also a gap in understanding among parents on the identifying symptom and consequences of delay in treatment.

- A quantitative study in Hyderabad by Dandona et al. (2001) showed lack of awareness among the general population about glaucoma[7] (2.4%), diabetic retinopathy[8] (28.8%), and night blindness (55.8%). Poor knowledge of the causes of night blindness in children is of concern, because about 40% of the Indian population are aged 4 to 15 years. Awareness and knowledge of night blindness during childhood is important, since vitamin A deficiency is common and is also associated with higher mortality in children.

- More than half of the respondents (54%) did not understand the importance of eye check-up for children below 5 years as per the study done in Indore by Vaseem et al. (2015).

- Nirmalan et al. (2004) discussed various misconception prevalent in the community. One of the general perspectives of the community as per the study conducted in South India was that Strabismus was not treatable. Further, some consider Strabismus as a sign of good luck. Parents did not think periodic eye check-up was important. Some looked up to traditional healers for primary level services for eye problems.

- In their study on awareness of eye diseases and satisfaction for eye care services in Indore, Vaseem K, Baig VN, Rai P, Swarnkar

Knowledge about eye-sight issues in general and among children, is limited. This needs greater focus on promotional activities for eye health, and the need for periodic eye check-ups.

6 Amblyopia is a vision development disorder in which an eye fails to achieve normal visual acuity, even with prescription eyeglasses or contact lenses
7 Glaucoma is a group of eye conditions that damage the optic nerve, the health of which is vital for good vision. This damage is often caused by an abnormally high pressure in your eye.
8 Diabetic retinopathy is a diabetes complication that affects eyes. It's caused by damage to the blood vessels of the light-sensitive tissue at the back of the eye.

M. (2015) found that knowledge about glaucoma and its treatment was seen in only in 41% of the participants. 60.3% of participants did not know about glaucoma in a study in Bihar.

The analysis of the above studies shows that knowledge about eye-sight issues in general and among children in particular, is limited. This points to the need for greater focus on promotional activities for eye health, and the need for periodic eye check-ups. Lack of awareness about eye problems, lack of community level facilities and programs for child eyecare - especially in rural India - tend to add to challenges that already exist.

1.5 Status of Eye Health Care

It is important to establish a pattern in the approach adopted by different countries when it comes to eyecare, and understand its dependence on population density and type of intervention, to explore if the same can be adapted in India.

VISION 2020: The Right to Sight is a global initiative for the elimination of avoidable blindness; a joint programme of the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB). About 90% of visually

impaired people live in low and middle-income countries. Almost 85% of blindness was attributed to avoidable causes, increasing the emphasis on advocacy, human resource development, infrastructure, technology development and partnerships for blindness prevention and control. However, some countries have not developed a national plan for Vision 2020 (Murthy and Vasisht, 2013).

It was observed that the public sector is the predominant healthcare provider in countries like Bhutan, DPR Korea, Indonesia, Maldives and Myanmar, while the private sector was the predominant provider in Sri Lanka and Thailand. In Bangladesh, India and Nepal, there is a mixed system whereby both the public and private sectors are significant eye healthcare providers. Notably, non-governmental organizations have made a big difference to eye care services in India and Nepal over the past three decades (Murthy and Vasisht, 2013). In both India and Nepal, more than 60% of cataract surgeries is performed by the NGO sector which only accounts for a third of all ophthalmologists, thereby reiterating the fact that efficiency increases output.

Murthy et.al. (2008) mentioned that many of the hospitals in India do not have a full complement of diagnostic and surgical equipment, infrastructure and supportive human resources to provide vibrant pediatric ophthalmology services. A significant number of hospitals in the country have either specialty trained or oriented ophthalmologists, and they are usually not supported by a trained pediatric team. According to Family Health and Development Research Service Foundation (2007) about half of the ophthalmologists are surgically inactive within the country. The inadequate number of ophthalmologists trained in pediatric ophthalmology and lack of eye care delivery models targeting children hinder quality eye care services in India (Nirmalan et al. 2004). Most studies are not very reliable; but they throw light on past prevalent causes and under-represent the true picture from the community.

Thus patient centric models in the west are not entirely adaptable in the context of developing countries like India owing to the difference in size of population. In those countries, there is no stigma attached to wearing spectacles. Their structured rehabilitation efforts are in place, thus making eye healthcare systems more successful. Collaborative efforts and civil society partnerships in countries like USA, Sweden, Finland, Japan, Singapore and Australia have produced positive results. Sri Lanka has an effective primary care network and immunization programs and along with Thailand can provide inputs to other countries on how to better their pediatric eye health systems. India, with its intensive skill training spearheaded by Orbis, enabled the development of the Pediatric Ophthalmology Learning and Training Centers, and have been providing quality training to pediatric ophthalmologists and ophthalmic personnel across the country.

An area for improvement in developing countries is to establish a multiple level system and referral linkage mechanism. This, coupled with community development and awareness initiatives can improve the levels of health seeking behaviour among people. For instance, LV Prasad Eye Institute (LVPEI) currently has 180 Vision Centers that provide primary care in the districts and villages of Andhra Pradesh, Telangana, Odisha and Karnataka. These are linked to Secondary Eye Care Centers, which are in turn linked to LVPEI Tertiary Centers in Visakhapatnam, Vijayawada and Bhubaneswar (Odisha). LVPEI's Center of Excellence at Hyderabad is at the apex of the Eye Care Pyramid. Although currently used in a bottom-up approach, the LVPEI Eye Care Pyramid originally evolved as a 'top down' model, which enabled the Institute to leverage its existing global and Pan-India linkages and facilitate implementation at the grass roots. The Government of India has adopted LVPEI's Pyramid as a model of Eye Care service delivery. Dr. Subhadra Jalali, Faculty and Head, Department of Retina, LV Prasad Eye Institute, mentioned that Malawi has good reflex screening facilities for detecting childhood cataract and amblyopia which could be adopted in India. However, in the Indian scenario, door-to-door screening would be difficult. But personnel in vision centers can be trained to identify children with pediatric cataract and glaucoma.

An area for improvement in developing countries is to establish a multiple level system and referral linkage mechanism.

The above facts demonstrate that there is no stereotypical approach that can be adopted as it is in the Indian perspective. The approaches across the globe are country specific and their success depends on the target population. The density of population, general spending on health infrastructure and attitudes towards eye health especially of children all of which have a bearing in the formulation of future methodologies.

Chapter 2

Importance of Child Eye Care

Eye healthcare is necessary because healthy vision influences overall development and quality of life of the individual and his/her interactions with the society. Visual impairment can affect employability, increase dependency and may cause social and cultural isolation. Eye health assumes greater importance when it comes to children, because visual functioning is a strong predictor of future academic performance in school-age children, and vision disorders during childhood may continue to affect health and well-being through the adult years. Regular eye healthcare can enable early detection and possible prevention of avoidable vision related problems, thereby increasing the probability of a more fulfilling life for the person affected. While efforts to make social infrastructure inclusive and disable friendly have been on the rise, they are insufficient. This section discusses the link between socio-economic factors and eye health, while also highlighting the importance of early eye care.

2.1 Economic and Social Impact

The societal burden of vision impairment and blindness is substantial in its impact on employment, Quality of Life (QoL) and the related caretaking requirements. Vision impairment also poses an enormous global financial burden as demonstrated by previous research, which has estimated costs of productivity loss. For instance, globally, it is estimated that vision loss costs $168 billion per annum in loss of productivity. Since about 80% of blindness is avoidable, evidence shows that treating and preventing blindness provides some of the largest returns on investment (RoI) compared with other health interventions. The limited need for infrastructure, low treatment costs, and relatively high potential for cost recovery for interventions such as cataract surgery, make interventions in eye care a compelling investment. This is especially relevant in low income countries, where prevalence of blindness and vision impairment far exceeds that of high-income regions.[9] For instance, the economic burden of uncorrected myopia in the regions of East Asia, South Asia and South-East Asia were reported to be more than twice that of other regions and equivalent to more than 1% of gross domestic product (GDP).

Children constitute the future of the country, and their health and well-being have a direct bearing on the future of the nation. Loss of vision is linked to economic development as poverty often increases the risk of vision loss. Conversely, vision impairment perpetuates poverty. According to McDonald and Taylor (2014), economic factors affect eye health, since majority of visually impaired people live in low and middle income countries. Lack of access to adequate nutrition, housing, sanitation, water, education and basic health services makes the poorer sections of society more vulnerable. This impacts overall health, including eye health (McDonald, Taylor 2014).

Globally, it is estimated that vision loss costs $168 billion per annum in loss of productivity.

9 https://www.iapb.org/wp-content/uploads/Trust-Investing-in-Vision-Making-a-Difference-across-the-Commonwealth.pdf

Visual impairment affects children's ability to learn, and leads to academic under-achievement and low levels of literacy at the societal level. Disabilities also disrupt the education of the care-givers.[10] In terms of employment, the vocational opportunities available to the visually impaired are limited in number and it is difficult for them to find avenues for self-employment. They would need better support in terms of easier loans and infrastructure assistance to earn a living from self-employment (Bigovic, et al., 2010); (Denninghaus, 2011).

The visually impaired are affected by the negative attitudes of their employers towards their employability (McDonnall, et al., 2013). Most workplaces are not equipped to accommodate visually impaired employees. The indifference to their plight, often creates a difficult work atmosphere for them. Workspaces are ill-equipped, and employers may have certain stereotypical perceptions about the productivity of visually impaired people.

Apart from hampering their productivity and functionality in day-to-day tasks, vision impairment also affects mental health. Visually impaired people have to depend on their family members, friends and other care-takers for physical, emotional, financial and social support. They need assistance with daily tasks.[11] The caregivers, especially parents, face a number of challenges as they will need to come to terms with the disability of their loved ones. This creates psychological stress that leads to impairment of quality of care. Any disability depletes the material wealth of the households affected – both for those affected and for their caregivers and other members of the family, since there are medical and rehabilitative treatment costs involved.

In a study on the caretakers of children affected by Primary Congenital Glaucoma,[12] it was found that it not only affects the wellbeing and health of the caretaker, but also indirectly influences the quality of care provided. Symptoms of depression have often been seen in primary care givers. This study found that prolonged disease and older aged children were significantly associated with lower quality of life of the caretakers. They face higher levels of debt, low property ownership and overall low standards of life.

10 The Social and Economic Impact of Poor Vision," Boston Consulting Group and Essilor, May 2012, https://vii-production.s3.amazonaws.com/uploads/research_article/pdf/51356f5ddd57fa3f6b000001/visionimpactinstitute-whitepaper-nov12.pdf
11 McDonald, Taylor 2014
12 Kantipuly, A. et al., 2019

The social impact of loss of vision leads to isolation from social institutions. They have limited choices for partners, and experience low self-esteem and other stigmas imposed on them. Their disability also makes them more vulnerable to abuse both from within and outside the households (McDonald, Taylor 2014). It is important to evaluate and measure the social impact and costs if one were to analyse solutions to tackle the effects of vision loss and facilitate reduced health costs, increase in productivity and improved quality of life (McDonnall et al., 2013). Further, rehabilitation needs to be prioritized, which can ease their experience of disability and enable greater participation in social, economic and political activities, in relation to the status quo. It is important that the provisions stated by the Convention on the Rights of Persons with Disabilities (CRPD)[13] be implemented, so that the visually impaired can participate in the economy. Use of Braille and other modes of digital assistance can facilitate the involvement of the visually impaired in all walks of life. Vocational opportunities suited to the needs of the visually impaired must be created and should be aided with placement cells, enabling employment according to one's qualifications.

Thus, from the above we can arrive at the following inferences:

1 Poverty often increases the risk of vision loss, even as vision impairment perpetuates poverty.

2 Loss of vision curtails available prospects of employment for those affected, and brings down the productive workforce of the society.

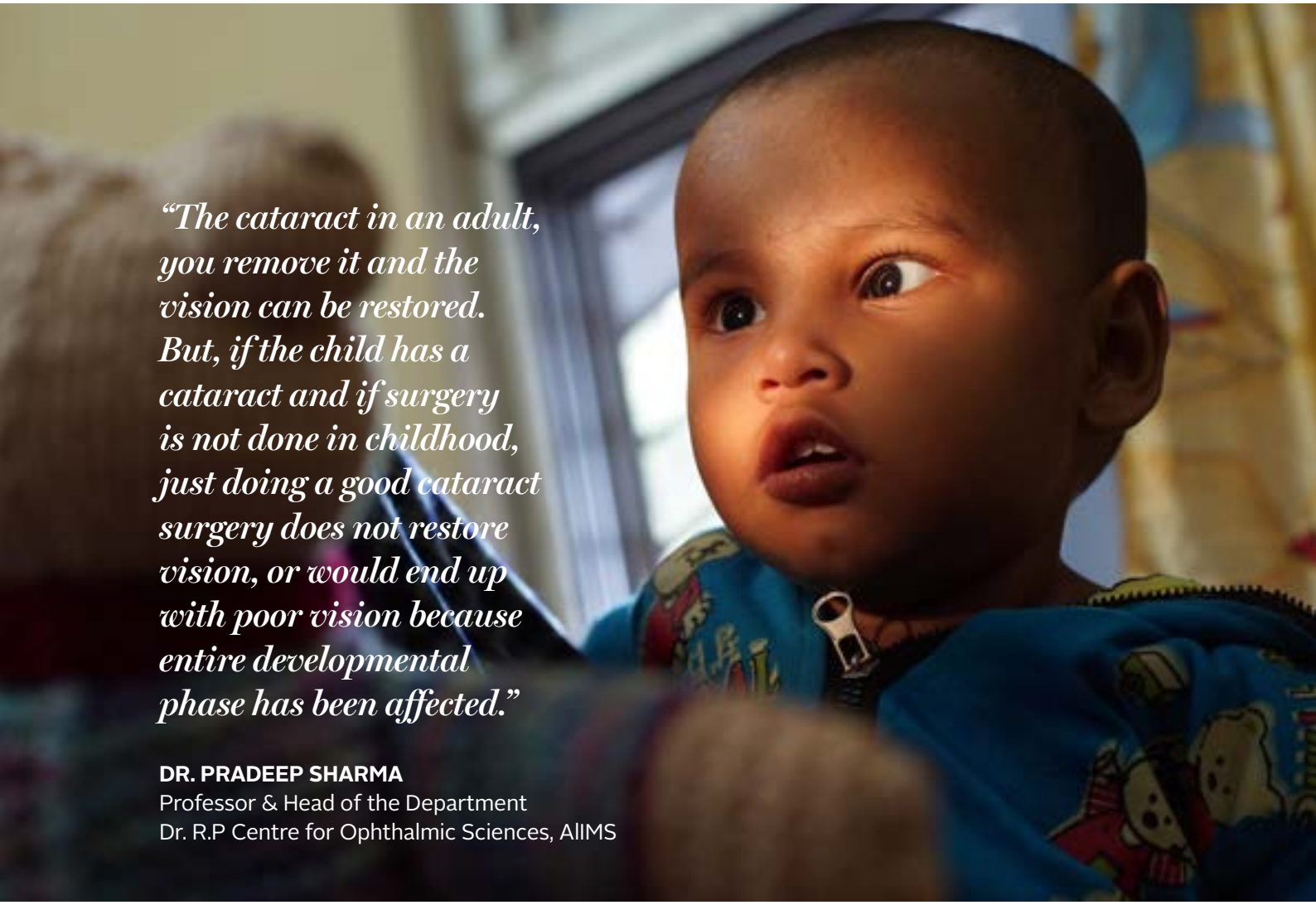
3 Visually impaired are affected by the negative attitudes of their employers towards their employability. Employers are riddled with stereotypes about the productivity of visually impaired persons.

4 Most workplaces are unwilling and unprepared to accommodate visually impaired employees. Indifference to their plight, often creates a humiliating work atmosphere for them.

5 Dependence on others often leads to depression and distress among the visually impaired. Any disability depletes the material wealth of the households affected – both for those affected and for their caregivers and other members of the family.

6 Social impacts of loss of vision also lead to isolation from social institutions. They have limited choices in partners, experience low self-esteem and other stigmas imposed on them.

13 The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (Source: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)



2.2 Economic Burden for Childhood Blindness in India

The economic burden of childhood blindness is more pronounced in developing countries in comparison to developed countries. Studies have shown that developing countries have 12 to 15 blind children for every 10,000 children, compared to 3 or 4 blind children per 10,000 children in developed countries (Solebo AL, Teoh L, Rahi J. 2017). Inequities in healthcare still exists in India along the lines of economic status, education, geography, caste and gender. Those from socio-economically deprived sections have the most difficulty in accessing healthcare services.

The impact of various civil society and government initiatives on eye healthcare needs have been analyzed in terms of the quality of vision and life indicators like Quality of Adjusted Life Years (QALY). QALY is a measure of the benefits of medical interventions and consequent health outcomes. In a research on economic burden of blindness of children,[14] Shammanna and Mannava (2020) found that the loss in Gross National Income

14 Shammanna and Mannava, 2020

(GNI) due to blindness would increase 3 times, cumulative loss would rise by 3.5 times and cumulative loss due to preventable causes by 2 times in 2020 compared to estimates from 1997. According to the study, the economic burden of blindness in India in 2020 would be INR 889 billion ($11.6 billion). Cumulative GNI loss due to blindness over the lifespan of the blind due to preventable and treatable causes in adults is INR 9,062 billion and INR 3,311 billion for children, for 10 and 40 lost working years, respectively. This can be attributed to the loss of economically productive years not of the visually impaired alone, but that of the caregivers as well.

The economic burden of blindness in India in 2020 would be $11.6 billion. But, early detection of 35% of preventable causes of blindness in children can hugely reduce the economic burden making investment in eye care imperative.

It also states that early detection of 35% of preventable causes of blindness in children can hugely reduce the economic burden of blindness in India. The study observed that over the years, increasing intervention and expansion in the area of eye healthcare has improved economic productivity in the country. It found that the economic productivity of blind persons in 2020 is INR 67 billion, an increase of 63.2% from 1997 estimates after adjusting to inflation. It can be concluded that the GNI loss is high even though the prevalence of blindness has decreased considerably in the estimates. This is because of increase in per capita income, economic productivity and increase in lifespan of the population and more people contributing to the labor force in general. This improvement in the economic productivity of the visually impaired may be attributed to social integration initiatives, and better access to affordable, quality healthcare and rehabilitation.

In order to decrease the burden of childhood blindness, some concrete steps can be taken. The reach and access of vaccination and immunization needs to be expanded. Since addressing childhood blindness at an early stage is important, school level screenings can prove to be impactful.

Therefore, from the above it may be concluded that:

1 The economic burden of childhood blindness is more pronounced in low-income and developing countries, compared to developed countries.

2 Inequities in healthcare still exists in India in terms of economic status; those from socio-economically deprived sections have most difficulty in accessing available healthcare services.

Chapter 3

Causes and Conditions

There are many different eye conditions and diseases that can affect a child's vision. When certain visual skills are limited or underdeveloped in children, learning becomes difficult. Most of the eye conditions in case of children are preventable or curable, which makes it even more important to understand the conditions and the causes, so that they may be addressed. This section discusses the prevalent eye health conditions of children across the world and their associated causes. Various causes for childhood blindness are described and relative variations in causes and type of eye health problems that exist across different countries have been discussed in the previous chapters. In the current chapter, the factors that have a bearing on eye health conditions such as socio-economic status of families, environmental conditions and lifestyle related factors are discussed.

3.1 Eye Health Conditions

The prevalent conditions of eye health as identified by various research studies are listed below for reference.

- Some of the most common conditions of visual impairment among children the world over are corneal scars, refractive errors, retinal pathology, congenital anomalies and congenital cataract. (Gogate P, Kalkua K and Courtright P, 2009).

- The Sightsavers International Report (2007) outlines Xerophthalmia,[15] congenital cataracts, globe anomalies, hereditary causes, congenital glaucoma, optic atrophy due to meningitis, Retinopathy of Prematurity (RoP) and uncorrected refractive errors as most common conditions leading to childhood blindness.

- Study by Murthy et al. (2002) found refractive errors, amblyopia, and retinal disorder[16] as significant conditions that reduced visual acuity among children.

15 The term Xerophthalmia covers all the ocular manifestations of vitamin A deficiency. Xerophthalmia can progress to irreversible blindness if left untreated. In endemic areas, vitamin A deficiency and xerophthalmia affect mainly children (particularly those suffering from malnutrition or measles) and pregnant women.

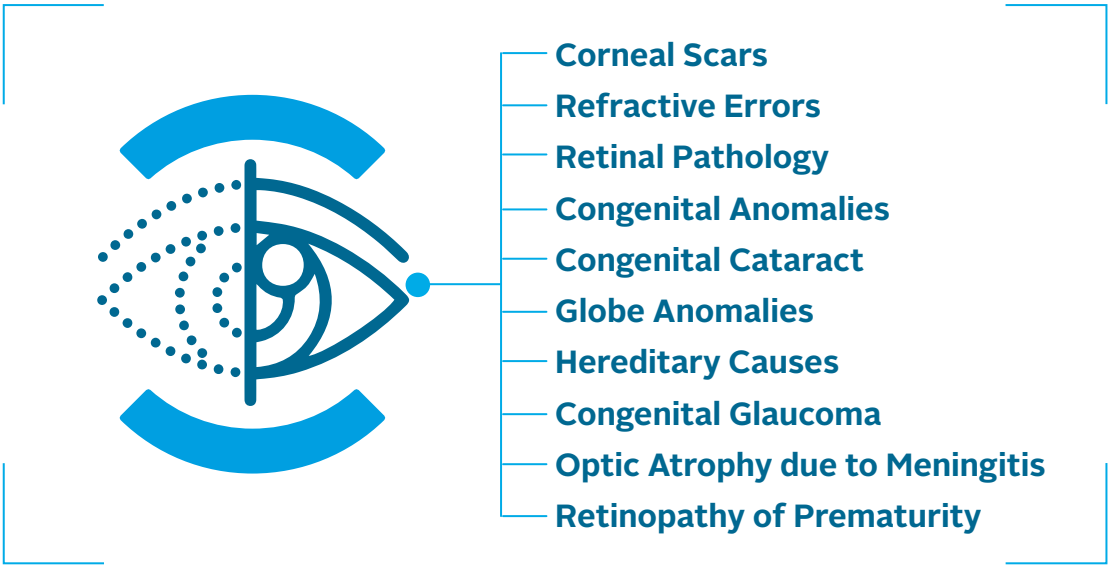
16 A retinal disorder or disease affects this very important tissue, which, in turn, can affect vision to the point of blindness

- Study by Panda et al. (2019) in tribal residential schools in Odisha found that the main conditions for visual impairment and blindness in urban areas are due to refractive errors, amblyopia and posterior segment anomaly, whereas deficiency of Vitamin A was detected only in children studying in the native schools.

- Lawreson and Downei (2019) also highlighted increase in leading conditions of blindness such as cataract, AMD,[17] glaucoma, and diabetic retinopathy over the years, and stressed on considerable scientific attention to dietary modification and nutritional supplementation for the prevention and treatment of these diseases.

- Gogate P, Kalkua K and Courtright P (2009) have recognized corneal scars, refractive errors, retinal pathology, congenital anomalies, and congenital cataract as the most common causes of Visual impairment among children.

From the above studies it can be clearly inferred that the various factors of visual impairment and childhood blindness include:



3.2 Causes of Avoidable Blindness

A majority of the world's blind live in developing countries. Malnutrition, inadequate health and education services, poor water quality, and a lack of sanitation can all contribute to eye disease. When people can't get help, or don't realize help is available, they stay entrenched in a cycle of extreme poverty – and become increasingly vulnerable to avoidable blindness.

Childhood blindness is an important indicator of child health and primary care services in a country. Many of the causes of childhood blindness are also the causes of mortality in children and this leads to increased mortality of blind children either from the systemic complications of the blindness-causing condition, or lack of adequate parental care and support. A few of the studies conducted in this area are as follows:

17 Age related Macular Degeneration is an eye disease that causes vision loss.

- In their study on the trends of avoidable blindness in children in the Indian context, Gudlavalleti and Venkata (2017) state that unlike in adults, less than 50% of the causes of blindness are avoidable in children. In South Asia it has been observed that the proportion of avoidable causes of childhood blindness varies between 28.8%-69.2%. The major causes of avoidable blindness are refractive errors and lens anomalies including congenital cataracts, whereas refractive error and strabismus are the reasons for ocular morbidity in children 15 years and younger.

- In India, there is currently no specific infrastructure for detection and management of childhood blindness at primary and secondary healthcare systems. At the tertiary level, very few centers (both government and nongovernmental organizations) are equipped to manage childhood blindness (Divya Senthilkumar et al., 2013).

- Wadhwani M, Vashist P, Singh SS, Gupta V, Gupta N, Saxena R. (2020) in their review of earlier researches on prevalence of childhood blindness found that in developing countries, 30–72% of pediatric blindness is avoidable, with most, in fact, being preventable.

MAJOR CAUSES OF CHILDHOOD BLINDNESS

- LACK OF ACCESS TO QUALITY EYE HEALTHCARE
- LACK OF ADEQUATE INFRASTRUCTURE FOR DETECTION AND MANAGEMENT OF CHILDHOOD BLINDNESS
- REFRACTIVE ERRORS & LENS ANOMALIES, INCLUDING CONGENITAL CATARACTS
- VITAMIN A DEFICIENCY, MEASLES, HARMFUL TRADITIONAL PRACTICES, RUBELLA
- LACK OF ADEQUATE PARENTAL CARE AND SUPPORT

Earlier studies in India showed a much higher prevalence of avoidable causes compared to recent studies. This temporal change reflects the success of primary healthcare interventions like immunization and supplementation programs that have made an impact on blindness attributable to vitamin A deficiency, measles, harmful traditional practices, rubella etc.

3.3 Eye Health Conditions

This section provides an overview of the different eye health problems among children in the Indian context. Through interviews with senior doctors and experts in the field of eye care, eye health conditions among children have been listed and discussed. It is juxtaposed with relevant reviews of literature on the conditions.

As part of the research, experts were asked to share their views on some of the common eye ailments that affect children in the Indian context. Mentioned below is the cumulative rating by different eye health practitioners about the status of child eye health in India. They have rated the status of child eye healthcare for a list of conditions that are of high prevalence:

- Childhood Cataract
- Childhood Glaucoma
- Strabismus (Squint)
- Amblyopia (Lazy Eye)
- Refractive Errors
- Retinopathy of Prematurity (RoP)
- Retinoblastoma
- Color Vision Deficiency

Rating was done on the following aspects > Magnitude of the condition, Awareness, Criticality of treatment in terms of diagnosis and management and Availability of treatment facilities in rural and urban areas.

	Magnitude	Awareness	Criticality of treatment (Diagnosis)	Criticality of treatment (Management)	Availability of treatment facility (Rural)	Availability of treatment facility (Urban)
Childhood Cataract	1	4	5	5	2	4
Childhood Glaucoma	3	4	5	5	4	5
Strabismus	3	3	3	4	2	2
Amblyopia	5	2	5	5	1	4
Refractive Error (myopia, hyperopia, astigmatism)	4.5/5	2.75/5	3/5	3/5	3.25/5	4.5/5
Retinopathy of Prematurity (RoP)	3/5	2/5	4.5/5	4.25/5	1/5	3.25/5
Retinoblastoma (Cancer of the eye)	2.75/5	2.5/5	4.25/5	4.5/5	1.25/5	3.25/5
Color Vision Deficiency	1.75/5	1.5/5	1.25/5	1.5/5	0.25/5	0.25/5
Other Common Eye Conditions: Conjunctivitis (redness and Dryness)	4.25/5	3.75/5	3/5	3/5	3.5/5	4.5/5

"In tribal communities there is still malnutrition. A large number of children used to go blind, they would come for treatment but mostly it was late, now it has decreased but it is still there."

– DR. SUBHADRA JALALI
Faculty and Head in the department of retina, LVPEI

Some observations from the rating exercise by experts:

- The magnitude of ailments in terms of the scale and occurrence in the Indian context is higher for conditions like refractive error, amblyopia and other common eye conditions like conjunctivitis and redness in the eye compared to conditions like childhood cataract, retinoblastoma and color vision deficiency.
- In spite of being widely prevalent, the awareness about refractive errors is low, more so among the less educated sections and rural areas. Same is the case for conditions like RoP, retinoblastoma and color vision deficiency.
- This underlines the importance of educational initiatives for parents and practitioners about recognizing the symptoms, and enabling early diagnosis of these conditions.
- While the treatment facilities are rated high for some of the conditions, it is relatively low for color vision deficiency, as there is currently no comprehensive treatment for the same.
- Availability of eye care facilities are expectedly low in rural areas compared to urban areas especially for cataract, strabismus, amblyopia and Retinopathy of Prematurity (RoP), all of which are mostly treatable with timely diagnosis.
- It points to the fact that while the 'criticality' of the treatment in terms of need for intervention at right time and importance to address it before it becomes the cause for permanent blindness is very high for most of the above conditions, the availability of treatment especially in rural areas – and in some cases, even in urban areas – is a challenge.
- Another major cause, in addition to childhood glaucoma, is the significant gap between criticality of treatment and the availability of a treatment facility.

Some of the common conditions in terms of symptoms, causes and treatment are highlighted in the glossary section. This includes information about specific conditions gathered from expert interviews, and the understanding developed from review of literature.

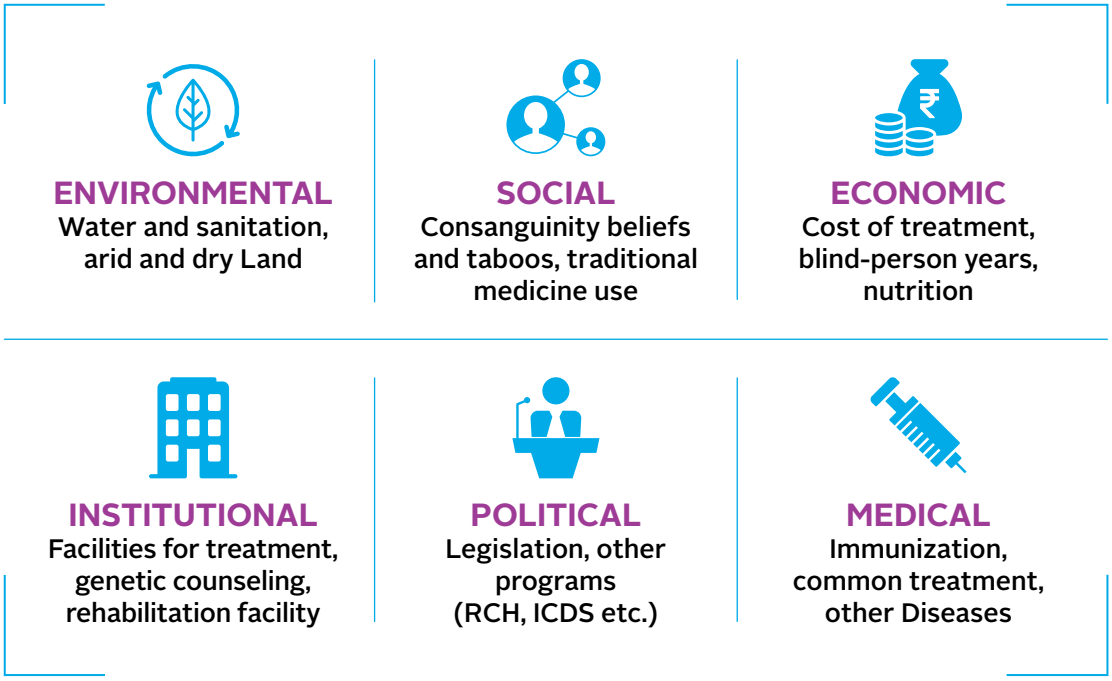
3.4 Causes of Childhood Blindness

Childhood blindness is an important indicator of child health and primary care services in a country. Many of the causes of childhood blindness are also the causes of mortality in children. This leads to increased mortality of blind children either from the systemic complications of the blindness-causing condition or lack of adequate parental care and support.

In their study on the trends of avoidable blindness in children in the Indian context, Gudlavalleti and Venkata (2017) state that unlike in adults, less than 50% of the causes of blindness are avoidable in children. In South Asia, it has been observed that the proportion of avoidable causes of childhood blindness varies between 28.8%-69.2%.

The major causes of avoidable blindness are refractive errors and lens anomalies, including congenital cataracts. Refractive error and strabismus are the primary reasons for ocular morbidity in children aged 15 years and younger. In India, there is currently no specific infrastructure for detection and management of childhood blindness at primary and secondary healthcare systems. At the tertiary level, very few centers (both government and non-governmental organizations) are equipped to manage childhood blindness (Divya Senthilkumar et al., 2013).

Review of scientific literature provides different causes of eye health issues among children, which range from family and hereditary factors to nutritional deficiency. Different environmental, social, economic, institutional, political and medical reasons affecting childhood blindness as categorised in Sightsaver India (2007) report are provided below.



According to National Center for Children's Vision and Eye Health (2016), the risk factor for vision problems in children is due both to genetic and environmental factors. Family history is a risk factor for vision disorders such as refractive error, as is premature birth. Further, presence of some vision disorders increases the likelihood of developing other vision disorders, such as Strabismus and Amblyopia. Several neuro developmental disorders (e.g., Cerebral Palsy, Down Syndrome, Autism Spectrum Disorders, Hearing Impairment and Speech Delay) are also associated with higher rates of vision problems.

Dandona et al. (1998) has listed out different causes of childhood blindness at different stages:

Genetic/Hereditary Causes: This includes varying degrees of genetic influence, retinal dystrophies[18] and optic atrophy.[19] Consanguineous marriages chiefly contribute to this.

Intrauterine Causes: Rubella infection during first trimester of pregnancy can cause various ocular anomalies. Toxoplasma infection during pregnancy may also result in ocular abnormalities. Another potential intrauterine cause of childhood blindness is optic nerve hypoplasia due to maternal use of alcohol or certain drugs during pregnancy.

Prenatal/Neonatal Causes: Infection of new-born due to presence of Neisseria gonorrhoea and Chlamydia trachomatis infections in mother can quickly lead to corneal involvement, blindness, ocular and systemic morbidity. Retinopathy of Prematurity (RoP) is a condition in which abnormal retinal fibro-vascular proliferation occurs in preterm infants due to interruption of the normal process of retinal vascularisation. The main risk factors for RoP are preterm birth, low birth weight, and fluctuating levels of blood gases (oxygen and carbon dioxide) during the first few weeks of life.

Infancy and Childhood Causes: Measles, Vitamin A deficiency, nutritional deficiency, injury lead to ocular diseases. Poor seating arrangement in the classroom is one of the causes of refractive errors in school age children.

Trauma: Most common cause of loss of vision in one eye. Ocular injury with callously disposed hypodermic needles as part of hospital waste has recently been noticed with increasing frequency in children.

A study by Murthy et al. (2013) examined children between the ages of 3 and 15 years and found that about 93% had severe visual impairment and blindness (SVI/BL). Pre-natal factors were responsible for at least 47% children whereas hereditary factors accounted for 23%. Cat eye syndrome as one of the most common single cause of SVI/BL and, taken

18 Retinal dystrophies (RDs) are degenerative diseases of the retina which have marked clinical and genetic heterogeneity. Common presentations among these disorders include night or colour blindness.
19 Optic atrophy is a condition that affects the optic nerve, which carries impulses from the eye to the brain

together with measles accounted for 22% of cases. The proportions of children with SVI/BL due to corneal scarring, retinal disease and lesions of the whole globe were similar; approximately 20-25% each.

A study by Khanna (2018) in schools for the blind found that congenital anomalies contribute to nearly 40% of the causes of childhood blindness. Further, retinal causes are on the rise in certain regions of the country, especially in the rural pockets. The study has identified only a few rare cases of Retinopathy of Prematurity (RoP) in schools for the blind, and estimated that there may be a rise in blindness from RoP in the future. Gogate et al. (2011) also highlighted that RoP is responsible for up to 15% of blindness in developed countries and up to 60% in middle income countries. In retinoblastoma, a genetic factor is among the commonest. One of the major problems faced by peripheral doctors is the late presentations of the case due to lack of awareness among parents.

Maternal factors include maternal infection with rubella and toxoplasmosis. Parental factors include Retinopathy of Prematurity (RoP), and childhood factors include Vitamin A deficiency, measles, external eye infections, harmful traditional eye medicines and eye injuries. Analysing childhood blindness, the frequently affected parts of the eyes include whole globe cornea (36%), lens (11%), retina (6%), optic nerve (5%). Rahi et al., (2017) reported vitamin A deficiency to be the most common cause of childhood blindness, whereas a study by Dondona et al. (1998) in south India did not find vitamin A deficiency as one of the major causes of blindness.

Based on the review of literature and interaction with experts, below is the categorization of causes of childhood blindness:

1. Malnutrition

Socio economic conditions of developing countries affect the status of child eye healthcare. Conditions like Vitamin A deficiencies are easily preventable through intake of food items like milk. Nutrition and sanitation go hand in hand. Diseases like diarrhoea, measles and respiratory infection, which are caused due to poor sanitation can affect the vitamin A levels of the child. Nutrition also has a direct effect on the development of glaucoma. Corneal conditions can induce secondary glaucoma.

"In most of the areas, it is still there in tribal communities where there is still a lot of malnutrition. But the large number of children who used to go blind, you would have seen many of these people used to come with white eyes."

– **DR. SUBHADRA JALALI**, HOD Retina, LVPEI

"See nutrition, sanitation, they go hand in hand, if you think of vitamin A deficiency, we have reduced the number of blindness from vitamin A deficiency to a great extent and it's not through supplementation only, it is overall improvement of the public health."

– **DR. ASIL SIL**, Chief Medical Office, Medical Director, Vivekananda Mission Ashram Netra Niramay Niketan

2. Lack of awareness/ comprehension

Younger children are often unable to comprehend that they have a vision problem. Unlike heart diseases or other illnesses, there may not always be noticeably clear symptoms for eye problems among children. Parents tend to be unaware of these issues. Myths and misconceptions prevent treatment of conditions like strabismus (Squint), and parents are not aware that it could be potentially blinding or might even be caused by retinoblastoma.

"Talking about when a child will start complaining is when the child's world starts to shift. It is because only by the time child is three or four years, starts going to school and is unable to view blackboard clearly, that is the moment when symptoms are identified."

– **DR. JAMEEL RIZWANA HUSSAINUDEEN**, Head, Binocular Vision/Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic, Sankara Nethralaya

3. Genetic Factors

A close connection has been found between Ophthalmology and Genetics. Multi-gene tests have transformed the diagnosis and treatment of ophthalmic patients. Certain conditions like glaucoma, retinoblastoma, pediatric cataract and strabismus can be transmitted hereditarily. These risks are higher among families where there are consanguineous marriages.

"There are many communities in India where you marry within the extended family. So in them cataract is higher. When it comes to parental history we say that if one parent is myopic then there is a 25% chance that the child can get refractive error or if both parents are myopic then this risk goes about twofold, so the child is at 50% risk of developing myopia."

– **DR. JAMEEL RIZWANA HUSSAINUDEEN**, Head, Binocular Vision/Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic, Sankara Nethralaya

4. Environmental Factors

Environmental factors like pollutants, toxic gases and chemicals, ultra violet radiation, temperature variations and variable humidity affect various parts of the eyes which lead to diseases like allergic conjunctivitis, cataract, glaucoma and dry eye (Shubrica, 2013). Global warming and ultraviolet radiation are the two most common causes of the human blindness. Global warming is responsible for the early onset and rapid progression of cataract (Johnson, 2004). While other environmental factors like radiation pollution, thermal pollution, heat pollution and water pollution are the main causes of chronic eye disorders, in case of conditions like myopia, genetics play a small role and are mostly caused by environment and lifestyle factors. Air pollution in the form of particulate matter can cause symptoms such as eye itching, burning eye irritation, sensory irritation, and allergic rhinitis (Shubrica, 2013). In excessively polluted cities like Delhi, cases of allergic conjunctivitis among children are higher.

5. Increasing use of digital devices

The American Academy of Ophthalmology (2018) reported that there is a marked increase in dryness and strain on eyes of children due to higher screen time. Children also experience headaches and blurry vision due to excessive use of computers and other digital devices. Electronic devices emit high-energy, short wavelength, blue and violet light, which may affect vision and even prematurely age the eyes. The exposure to blue light could contribute to eye strain and discomfort and may lead to serious conditions which may later lead to age-related macular degeneration (AMD) that can cause blindness. Children tend to spend more time indoors than outdoors, playing on electronic devices. This, coupled with the lack of exposure to sunlight affects the growth and development of the eyes and vision, which contributes to an increasing number of cases like myopia, or near sightedness, in younger people.[20]

"Rural schools are having online classes. Children in both rural and urban areas are learning from digital medium. So refractive error is going to increase in the future."

– **PARIKSHIT GOGATE**, Trustee and Ophthalmologist, Community Eye Care Foundation, Dr. Gogate's Eye Clinic, Pune

"Current preventative model states that even two hours of outdoor activities is recommended for every child who is at risk of myopia."

– **DR. JAMEEL RIZWANA HUSSAINUDEEN**, Head, Binocular Vision/Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic, Sankara Nethralaya

Young children who play video games and other digital devices before attaining the required ocular development are more prone to myopia. The use of smart phones and tabs have replaced outdoor games and have increased the risks of myopia and binocular anomalies. These gadgets affect the ciliary muscles and creates short-sightedness. Vitamin D deficiency that comes from lower exposure to sunlight can cause psychological and other health problems. American Academy of pediatrics recommends that the total time a child spends on gadgets should not exceed an hour per day.

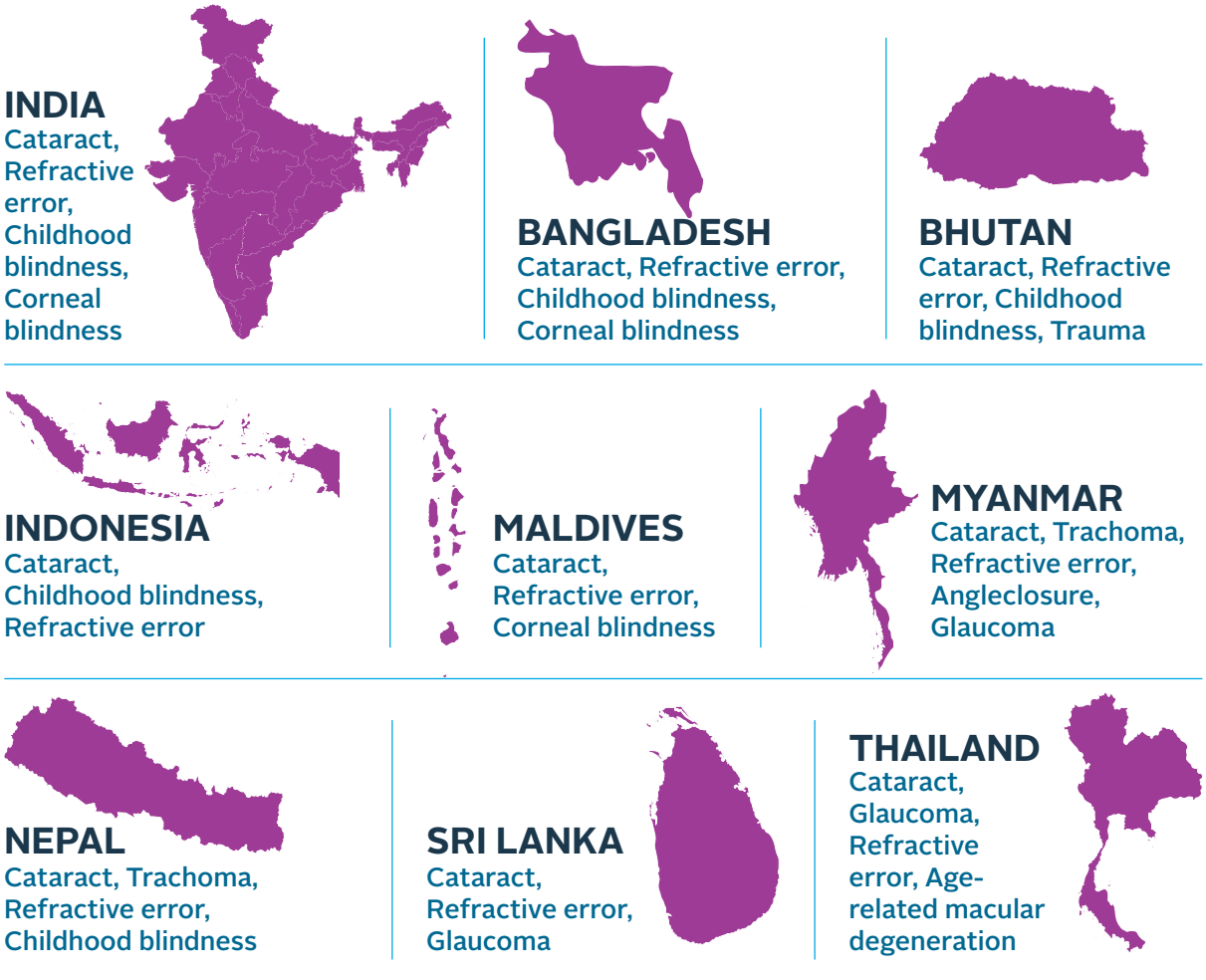
20 https://www.aoa.org/newsroom/the-21st-century-child-increased-technology-use-may-lead-to-future-eye-health-and-vision-issues

3.5 Geographical Variation in the Prevalence and Causes of Eye Problems

There are certain eye health issues prevalent across different countries and certain issues that are specific to particular countries. The variations are due to a multitude of factors such as health status, climate, lifestyle and socio-economic development, which impact the eye health of the population. Gilbert et al. (2017) has argued that measles, vitamin A deficiency, childhood cataract, Retinopathy of Prematurity (RoP) and cerebral visual impairment are the leading causes of visual impairment in children globally.

Around 23% to 44% of problems such as albinism, congenital cataracts with family history are the predominant causes of childhood blindness in America, Europe, certain parts of Asia and Western Pacific region. In middle-income countries such as Brazil, South Africa, India and China, Retinopathy of Prematurity (RoP) has been rapidly increasing and is seen to be the dominant cause of childhood blindness (Barret, 2005). In low income countries, cataract and corneal diseases are the most common avoidable causes of childhood blindness. In Ethiopia, corneal scarring is seen to be the commonest cause of childhood blindness. (Parikshit & Clare, 2006).

Sightsavers International report (2007) lists out the most prevalent conditions for blindness in different south Asians countries as below:



Indian Context

Geographical location affects access to eye healthcare in India. In the north eastern parts of India, owing to the hilly terrain, access to healthcare is difficult, and this applies to pediatric healthcare as well. There is lack of tertiary centers across these states. Southern and western parts of India have better access to eye health services compared to more populous states like UP, Bihar or Rajasthan, or remote and tribal areas.

"Even the per capita income in the north eastern region, it is lesser than the per capita income of some of the developed states of India, so poverty is directly related to their scenario of blindness."

– **DR. HARSHA BHATTACHARYA**, Founder, Medical Director and Trustee of Sri Sankaradeva Nethralaya, Assam

Even within the states, there exists disparity between urban and rural areas. While there might be one ophthalmologist for a population of 10,000 in the urban areas, the rate in rural areas might be one ophthalmologist for every 2,50,000 to 500,000 people. Most of the institutes are in the urban area as it is easier to set up facilities for general anaesthesia and post-surgery recuperation. Such services are not available in rural areas.

"Forget about the rural population, they do not even have proper food, how will they go to doctor to get their eyes checked?"

– **DR. TS SURENDRAN**, Vice Chairman, Director Pediatric-Ophthalmology, Sankara Nethralaya

"For rural poor, the neglect is more, the ability to receive the services is less. Even if they are prescribed glasses, either they cannot afford it or the child loses them, it may not be replaced for him. This also affects the vision."

– **DR. PRADEEP SHARMA**, Professor and Head of Department, Dr. R.P Centre for Ophthalmic Sciences, All India Institute of Medical Sciences

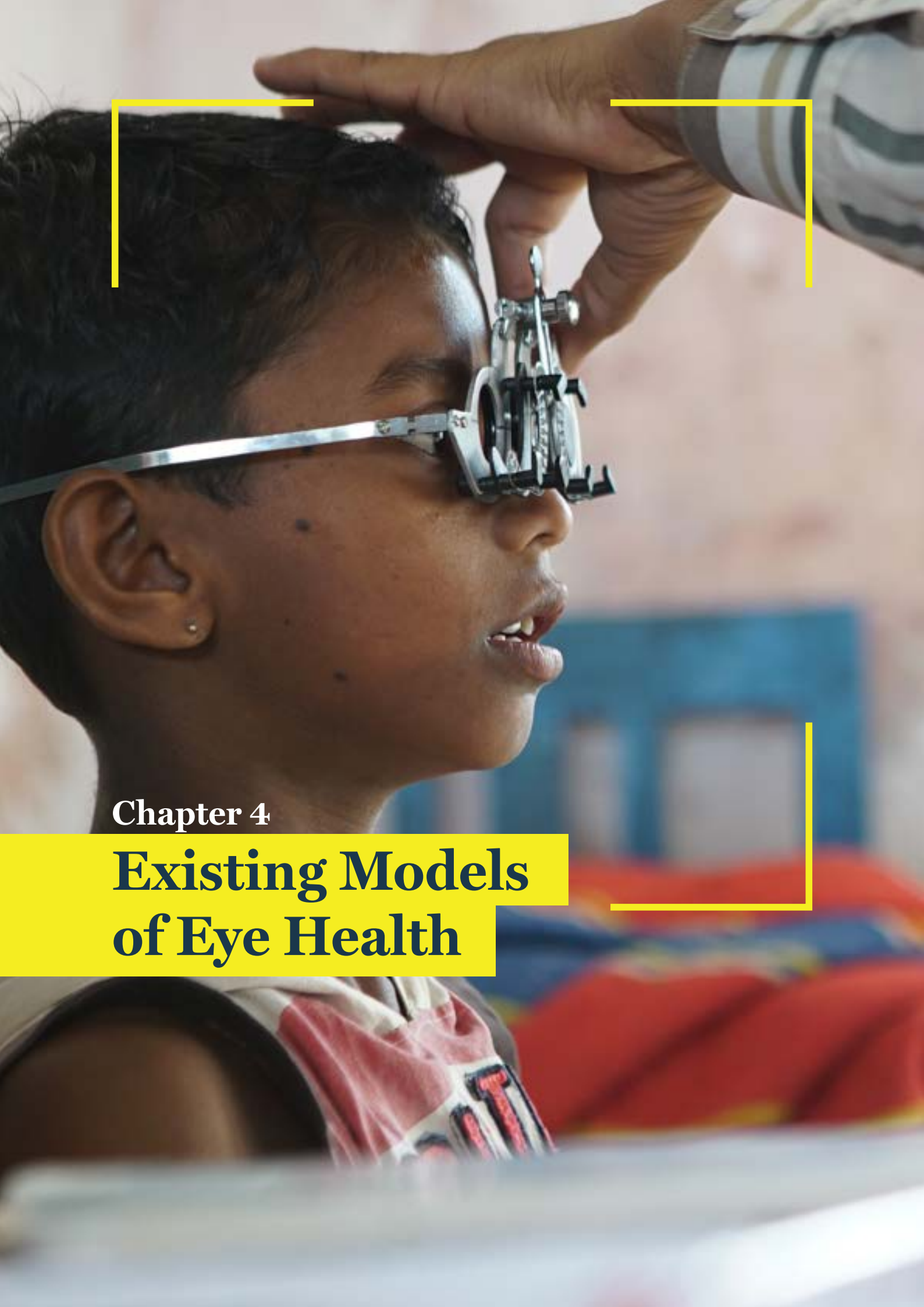
Deepening economic and social disparities also affect the status of national level eye health as the magnitude of problems faced by persons from lower economic backgrounds, and women, are more than that of the others. In the socially and economically deprived areas, neglect and inability to access services affect their eye health. In India, children in the rural set up have lower prevalence of myopia compared to urban children. In terms of Trachoma,[21] in 2017 many media reports had said India is a trachoma free country. Trachoma has two forms —active and sequelae. While active trachoma is seen among children, sequelae is seen among adults. A Health Ministry commissioned survey conducted by AIIMS experts between 2014 and 2017 has shown active trachoma prevalence of only 0.7 per cent in children aged one to nine years, who were examined. "We have eliminated active trachoma as a public

21 Trachoma is a disease of the eye caused by infection with the bacterium Chlamydia trachomatis. It is a public health problem in 44 countries, and is responsible for the blindness or visual impairment of about 1.9 million people. Blindness from trachoma is irreversible (Source: https://www.WHO.int/news-room/fact-sheets/detail/trachoma)

health problem and will seek WHO certification for this. This is a step forward after polio and yaws elimination," Health Minister JP Nadda said.

To sum up, there are different causes of childhood blindness in India, ranging from lack of nutrition to changes in the lifestyle, to genetic factors as outlined in this chapter. The magnitude of ailments in terms of the scale and occurrence among children in the Indian context is higher for certain conditions when compared with others. In addition to increasing facilities, initiatives that build awareness among parents, community and the practitioners about recognizing symptoms and enabling early diagnosis of these conditions will be of significance.

While there might be one ophthalmologist for a population of 10,000 in the urban areas, the rate in rural areas might be one ophthalmologist for every 2,50,000 to 500,000 people.



Chapter 4

Existing Models of Eye Health

India was the first country to have a National Program for Control of Blindness (NPCB) in the world. A Resolution of the Central Council of Health & Family Welfare at its meeting in the year 1975 said, "One of the basic Human Rights is to see and, therefore, it is to be ensured that no citizen goes blind needlessly; or being blind does not remain so, if, by reasonable deployment of skill and resources, his eye sight could be prevented from deteriorating and if already lost could be restored."

The program was launched in 1976 as a 100% centrally sponsored program to reduce prevalence of blindness from 1.4% to 0.3%. The National strategy for Prevention and control of Blindness adopted policies that included:

- Dissemination of information about eye care through mass communication.
- Emphasis on ocular health among children and vulnerable sections of society.
- Augmentation of ophthalmic services so that relief can be given in the shortest possible time.
- Establishment of proper infrastructure for community eye healthcare.

The NPCB also found mention in the National Health Policy in 1983. It has been successfully supported by the Central Government, and resource allocations have been made as a priority in the country. Blindness control activities form an important strategy for action under the National Rural Health Mission (NRHM) with at least four indicators monitored at the community level:

- Cataract surgery rate
- Number of children with refractive errors provided with glasses
- Percentage utilization of donated eyes
- Number of teachers trained in vision screening

India was the first country to have a National Program for Control of Blindness (NPCB) in the world.

4.1 Preventive and Rehabilitative Approach of Child Eye Care in India

Following are the two main approaches to healthcare in general and eye healthcare in particular:

PREVENTIVE APPROACH

Prevention of eye health problems usually happens outside the eye care center. Immunization, nutrition and education programs are the means to it. For instance, in case of Retinopathy of Prematurity (RoP), it is necessary to keep a check on whether the mother was administered an antenatal steroid injection, or whether there was too much oxygen given at the time of delivery. These are the responsibilities to be taken up by the neonatology, obstetrics and gynaecology departments. There are many government programs that provide free services and reimbursements for these procedures.

Mandatory school screening, timely checks during childhood, and regular supply of primary health services at the community level are the features of ideal preventive eye healthcare model. This can increase awareness among pregnant women about immunization and possible deficiencies and infections that can be contracted by the unborn child. Regular eye examinations at the family level would be useful. Government initiatives like *Rashtriya Bal Swasthya Karyakram* (RBSK) and *Ayushman Bharat* are also focusing on these. The National Blindness and Visual Impairment Program which has been running for 30 years has now expanded its coverage to include not just cataract but other retinal problems like glaucoma, retinal diseases, squint and refractive errors.

An important method in the preventive approach is to educate teachers to identify vision problems – to check students' vision and look for eye reflex action, identify squint, and refer them to the doctors. However, teachers in India are often overburdened with work responsibilities, so it is uncertain as to what extent they would be able to shoulder such programs.

REHABILITATIVE APPROACH

India witnesses 33 million births daily, which stands at 66 million eyes that need eye examination. Western countries have neonatal care that is inclusive of basic eye check-up. Ideally when a child is diagnosed with blindness, they should be referred to a low vision clinic, and then put on a trial of low vision gadgets to improve their vision. A child who is totally blind should be enrolled in various rehabilitation centers, engage in braille education and given

occupational therapy. RBSK guidelines also explain a simple eye check up with a torchlight examination. However, it is not regularly followed in the country. Even for treatable conditions like cataract, owing to lack of timely detection, children end up in blind schools.

Dr. Kasturi Bhattacharjee, Director, Clinics and Academics of Sri Sankaradeva Nethralaya argued that rehabilitation is the process of restoring functional ability and improving the quality of life and independence in affected children. All types of rehabilitation are important. Psychological counselling and occupational therapy are essential. Special educators are needed to facilitate their overall development, to educate them about their capabilities and make them self-dependent. They also need to keep in mind that severity of diseases may vary from one child to another. Children with mild diseases can be helped with an ophthalmic evaluation on a regular basis and prescription. But if there are problems where vision is already impaired, then visual rehabilitation and guidance on how to use devices require intensive follow-ups. Expanding the accessibility of educational pedagogy for children with vision problems is also necessary. Rehabilitation is necessary to enhance children's clinical and other technical skills so that they can stay productive in the society.

The National Program for Control of Blindness (NPCB) has now become part of The National Rural Health Mission (NRHM), The National Rurban Mission (NRuM) and will be eventually integrated into *Ayushman Bharat*. The NPCB and many other civil society organizations have set up rehabilitation partnerships in relation to vision units. However, the model does not have the potential for scale up. Facilities are in big hospitals and in cities and therefore access to rehabilitation is limited to people in those areas.

Eye health is not a part of maternal and child health programs. There are not many facilities at the state government levels. For instance, the R.P Centre at AIIMS functions as a community oriented center for blindness. The Government's efforts in rehabilitation of visually impaired children are through the RBSK. Recent efforts involve setting up early intervention centers at district levels with equipment, medical team (general doctor and an optometrist), special educator and other facilities. These initiatives facilitate early detection of all disabilities including learning disabilities and creating a one-stop center for treatment.

Other than government facilities, private centers generally refer persons eligible for rehabilitation to their respective state government's hospitals, who are then expected to issue them a 'visually impaired' certificate that allows them to have access to some services. Civil society organizations like Sankara Nethralaya have low-vision clinics and rehabilitation centers. However, most organizations and facilities use the preventive approach and do not offer rehabilitation. In the Indian ecosystem, focus is still on treatment, and not enough on rehabilitation. Ideally, an empowerment approach which works towards identifying eligible persons for rehabilitation would be effective.

At the community level, most of the rehabilitation activities are initiated by NGOs and not the private sector. In the facilities that are supported by Ministry of Social Welfare, community rehabilitation falls under social welfare and not health, and that leads to fragmentation and lack of coordination in the existing community. It is necessary to set up community level eye care services with both private sector and NGOs delivering preventive and rehabilitative services. Apart from school screening programs, other initiatives include Vitamin A supplementation programs, awareness programs and examination or screening of every new-born.

"If enough counselling is not done, that means you are going to leave behind lot of children who are actually identified but did not access the required eye health services. After treatment, detailed counselling at the end is given to the parents. It is important to make them understand that their financial investment can be in vain if follow-up is not done."

– **DR. RISHI RAJ BORAH**, Country Director, Orbis India

The literature available on eye health also suggests that the status of rehabilitation in developing countries is inadequate. Therefore, the following preventive actions can help minimise children's eye related issues to a large extent:

Taking Regular Breaks
after every 30-40 minutes of reading, writing, or playing on the computer is recommended

Protection Against Sun Damage

Increase Time Spent Outdoors

Intake of Nutritious Food

Scheduling Regular Eye Check-ups

Encouraging Healthy Eyecare Habits in Children

Other than healthcare staff and ophthalmologists, teachers and caregivers also play a major role in screening and identifying eye issues among children. Hence, it is important to make sure that caregivers, schools and community-based rehabilitation programs play their role in providing children with timely eyecare. Often, the financial aspect is seen as an impediment by the individuals and their families, and as a reason for not being able to opt for adequate treatment. However, in the long run, cost of special equipment and the expenditure incurred in the care of a visually impaired child is way higher than the treatment cost. This awareness needs to be disseminated to make all relevant stakeholders understand the importance of a preventive approach to child eyecare.

Dijk (2007) discusses the importance of providing care for children with vision impairment. She advocates comprehensive care, social and educational care, responsibility, and coordination. Comprehensive care involves diverse groups such as eye hospitals, schools and community programs. Starting from locating people with visual problems to providing care irrespective of age, gender and/or community is necessary. Once identified, these children can be sent for regular follow-ups. Comprehensive care also involves providing training and counselling to people who are part of the eco-system that the visually impaired child inhabits.

The suggested focus of rehabilitation is as below:

- Early detection, diagnosis & intervention.
- Improve, facilitate, stimulate and/ or provide services for people with disabilities, their families and attendants.
- Medical rehabilitation i.e., management of curable disability, and reducing the disability to the extent possible.
- Social, psychological and other types of counseling and assistance.
- Training in self-care activities including social etiquette, mobility, communication, and day-to-day life skills with special provisions as needed.
- Provision of technical, mobility and other devices.
- Specialised education services.
- Community rehabilitation of disabled with a focus on blind persons.
- Vocational rehabilitation services including vocational guidance, training, open placement, and self-employment.
- Certification of degree of disability and provision of available concessions/ benefits.
- Community awareness, advocacy, empowerment and follow-up (Jose & Sachdeva, 2010).

4.2 Existing Models of Child Eye Care in India

Based on the stipulates of the NPCB and NRHM, different states of India have adopted different approach to address the issue of child eyecare in India:

Most of the current eye care models in India are focused on screenings and surgeries. They include school screening, consequent referral and community-based eye health programs. At the school level, focus is to train teachers, which is followed by organizations like Operation Eyesight, Orbis India where the teachers take responsibility for screening and referral of the students of their respective classes. The community-based eye health program is time consuming as it requires connecting with training and sensitizing *Anganwadi* (a type of rural childcare center) and Integrated Child Development Services (ICDS) workers for screening and referral of children with eye problems.

The current eye healthcare delivery system is hinged on coordination between the not-for-profit sector and the government. Government support can be accessed in two forms. First, government aids training institutions, enabling greater number of people to be trained through monetary assistance. Second, it assists in the form of cost sharing and reimbursement services rendered. NGO sector relies on government in areas of advocacy, reimbursement, subsidized costs for surgeries or spectacles, where the standard operating procedures of the government come in handy.

4.3 Existing Programs and Facilities

In this section, some of the important initiatives undertaken by hospitals and other institutes in providing quality eye care in India are discussed. This is drawn from both literature review and interactions with

experts who are closely associated with one or more of these organizations. In India, **Orbis** is known for establishing pediatric ophthalmology and have contributed to effectively managing pediatric eye related anomalies. **Sightsavers** is focused on multi-sectoral engagements; **Operation Eyesight Universal** focuses on community-based vision centers and rehabilitation. **Aravind Eye Care** has worked in providing pediatric ophthalmology based solutions, and **R.P Centre** is the biggest residential program that has been involved in training students in pediatric ophthalmology. Organizations like **Christoffel-Blind Mission (CBM)** and **Sightsavers** have succeeded in a coordinated resource sharing approach towards eye healthcare.

To better understand the current interventions, we need to understand the existing policy frameworks and their drawbacks in addressing specific, targeted and focused visual impairments.

Rashtriya Bal Swasthya Karyakram (RBSK) was launched under the National Health Mission in 2012 and is an important milestone in eye healthcare of children. Under the RBSK, every child at birth should be screened by existing health manpower. Community level screenings are to be carried out by mobile health teams at *Anganwadi* centers and government schools. Under this program there are district eye health centers as part of district early intervention centers, where every child is examined at birth by the pediatrician. This includes an eye check-up.

Under RBSK, every child at birth should be screened by existing health manpower. Community level screenings are to be carried out by mobile health teams at *anganwadi* centers and government schools.

Some of the short comings of the RBSK are:

- The original RBSK document covered certain birth defects and deficiencies such as those of thyroid, nutrition problems, cleft lip, congenital heart disease, but it did not cover eye health. Currently, the document includes a few eye diseases, namely, cataract, congenital cataract, squint, development delays and RoP for which children are screened at birth.

- There also lies the need to train medical personnel to carry out simple eye health tests, so that they can detect refractive errors, cataract or retinoblastoma early on in the children, simply by noting how the reflexes are differentiated.

In India – as discussed in the previous chapter – issues pertaining to child eye healthcare come under the National Program for Control of Blindness (NPCB). The World Bank group approved Blindness Control Project aims to improve the NPCB's quality of service and expand its treatment capacity. The objectives are:

- To upgrade the quality of cataract surgery
- To expand coverage to underprivileged areas
- To reduce the backlog of untreated cataracts to lower the prevalence of cataract
- To reduce blindness by more than 50% by performing surgeries
- To develop human resources and institutional capacity for eye care, promote outreach activities and generate public awareness

Though the objectives are clearly defined, the program has a few gaps in addressing child eye health issues:

- The functionaries of this program, while familiar with adult problems like cataract, diabetic retinopathy or glaucoma, often lack the requisite skills to address children's conditions.
- Child specialists are mostly concerned with routine immunization / prescribed vaccinations, nutrition, breast feeding, congenital heart disease etc. They deal minimally with eye healthcare. Therefore, this gap at the curriculum level needs to be addressed.

"So, the main gap is that there is no clear understanding that a baby's eye and vision is whose ownership. Is the baby's eye vision ownership of the pediatrician, the child health specialist or is it the ownership of the ophthalmologist?"

– **DR. SUBHADRA JALALI**, Faculty and Head in the Department of Retina, (LVPEI)

Besides the above listed government initiatives, listed below are a range of programs which have a more specific approach to child eye care. These programs also adopt more sophisticated and modern treatment facilities:

ARAVIND EYE CARE SYSTEM

Aravind Eye Care System, a Center of Excellence, is dedicated to eliminate avoidable blindness by providing quality eye care to children through their pediatric ophthalmology program. They also focus on community work and research, and promote community output services and screenings in NICUs.

LIONS CLUB INTERNATIONAL FOUNDATION

Lion's Club International Foundation (LCIF) is a non-government organization based out of Chicago and has a flagship program called 'Sight First'. Lion's Club International's initial focus was on cataract, to establish centers to provide surgeries, support services, conduct screening camps and create infrastructure for further training. In 2004-05, they graduated towards the concept of 'comprehensive eye care' which included childhood blindness. Currently they aid with infrastructure development, service delivery and human resources to eye care organizations that have been identified by them.

LV PRASAD EYE INSTITUTE (LVPEI)

LV Prasad Eye Institute (LVPEI), is a referral center for treatment of eye conditions in children and has contributed towards initiating programs related to Retinopathy of Prematurity (RoP). They have a dedicated institute for treating retinoblastoma in children. They have succeeded in creating eye care models where they have trained a number of ophthalmologists, pediatricians and neonatologists in identifying conditions like RoP. In Hyderabad, they have 100% coverage of every Neonatal Intensive Care Unit. LVPEI has one of the biggest children's eye care programs in the world with its large network of rural centers at both primary and secondary level.

OPERATION EYESIGHT UNIVERSAL (OEU)

Operation Eyesight Universal is an international development organization which launched the Operation Eyesight Universal Institute for Eye Cancer, world class institute, at the LV Prasad Eye Institute in Hyderabad, India. To combat the growing incidence of ocular cancer in India, the facility provides quality, comprehensive cancer treatment for children and adults, all at low or no cost. They partner with 32 hospitals and have 97 health centers spread across India.

They have developed different community eye health models to go beyond the scope of the hospital and intervene in target communities, while also supporting hospital upgradation. One of these community-based models, Vision Center Based Community Eye Health Project focuses specifically on child eye healthcare.

ORBIS

India Childhood Blindness Initiative is the flagship program of Orbis, which was started in 2000 with the establishment of a children's eye center at Dr. Shroff's Charity Eye Hospital in Delhi. Since then, they have established 33 children's eye care centers across 17 states in India. The availability of pediatric ophthalmology service care was 1 for 400 million in India in 2000. With Orbis's contribution, it has improved to 1 for 20 million in the country.

Orbis has a two-phased approach. The first phase helps build partner capacity and strengthens the quality of services. The second phase focuses on infrastructure development and service delivery. Each institution houses a dedicated pediatric ophthalmology team consisting of pediatric ophthalmologists and other pediatric ophthalmic personnel, who attend training in pediatric ophthalmology, pediatric anaesthesia and pediatric counselling. The REACH (Refractive Error Among Children) program of Orbis, functions across 15 districts of India to fight the most common cause of avoidable blindness among children, i.e. refractive error.

DR. RAJENDRA PRASAD CENTRE FOR OPHTHALMIC SCIENCES – AIIMS (R.P CENTRE)

R.P Centre is the epicenter of a national program for control of blindness. The first ever department of community ophthalmology in the country was set up in R.P Centre in 1992. Before then, there was no organized public health eye care facility in India, and community ophthalmology was limited to eye camps. The first community ophthalmology department was set up with the realisation that community ophthalmology must extend beyond eye camps, and that there was a need to focus on the causes of eye conditions, to tap into available interventions and work towards the skilling of human resources.

SANKARA NETHRALAYA

Collaborating with Orbis, they have screened over 3.25 lakh children in three years, and have worked towards creating awareness about refractive error. The Pediatric Ophthalmology department treats common eye problems in children. Other eye problems that are treated are tumours of retina or ptosis, drooping of eye lids, congenital birth cataracts, congenital glaucoma, birth glaucoma and tumours like retinoblastoma. Each year, they serve around 25000 children and perform around 3000 pediatric surgeries.

VIVEKANANDA MISSION ASHRAM

Vivekananda Mission Ashram had started out as an educational program aimed at educating girls. It later ventured into setting up a general college, a school for visually challenged and then a rehabilitation training center for the visually challenged. It was involved in a joint program with the Government from 2009-2013 as part of the Sarva Shiksha Abhiyan, to address the education needs of children with special needs. Currently with the help of Orbis, they are engaged in school level screening programs that have covered over four lakh students in three years.

4.4 Patterns in Seeking Child Eye Care

The general pattern observed in seeking care for eye health issues may be categorized as under:

- In many cases parents tend to blame previous injuries for the refractive errors and other problems without knowing the actual causes.
- People are more reluctant to seek healthcare, partly out of ignorance, when the child exhibits symptoms of vision disorders or has serious nutritional deficiencies like vitamin A deficiency.
- Parents are also discouraged by their apprehensions about the clinic, the procedures and the cost involved.
- It is more likely that the child with a problem in vision in one eye would have got habituated to using the other eye. Unless a screening is done, there is limited scope for the family to discover that the child has been suffering from a vision problem. Screenings should be done at neonatal stages and even in pre-schools.

Kalia, Amy et al. (2017), in their study on impact of late surgical process on blind children, found that treatment for blindness, even at a late age, can result in significant improvements in a child's quality of life. It shows that after treatment for congenital cataract, patients are able to acquire proficiency in an array of visual dimensions, ranging from basic functions such as acuity and contrast sensitivity to more complex abilities such as face localization and classification, spatial imagery and so on.

A change in the trend for causes of childhood blindness that indicates the successful implementation of various programs related to healthcare, immunization, and vitamin A supplementation, has made a positive impact by decreasing the burden of CHB. This trend is supported by the evidence that there has been a significant reduction in vitamin A deficiency in India over the past two decades (Wadhwani M, Vashist P, Singh SS, Gupta V, Gupta N, Saxena R. 2020).

"The nature always gives enough symptoms. If these symptoms are shown by the child it should be mandatory for the parents to take the child to a pediatric ophthalmologist."

– **DR. TS SURENDRAN**, Vice Chairman,
Director Pediatric-Ophthalmology, Sankara Nethralaya

4.5 Challenges or Gaps in Child Eye Healthcare

The following section delves into some of the main challenges impinging on the availability and access to child eye health services in India.

In India, broadly speaking, the major challenges identified in eye health centers revolve around poverty, inequity in access to eye healthcare, lack of affordable quality services and lack of awareness among vast sections of the population. We have classified the challenges into two, depending on the position one is at, namely, 'Demand' and 'Supply'. 'Demand' refers to the challenges from the individual/community/societal standpoint. 'Supply' refers to the gaps and challenges at the institutional level, be it in terms of infrastructure or quality of services available for child eye care. This section will provide an in-depth view of the nature and extent of these challenges.

Demand Side

Lack of Awareness About Child Eye Healthcare

People usually lack the awareness that in pediatric cases, early intervention is better. Some people also resort to traditional healers instead of trained medical professionals to cure eye problems. Regular eye check-ups, irrespective of the symptoms, need to be popularised, so that early detection of refractive errors, strabismus and lazy eye can be made possible. There are very few specialised human resources in rural areas for pediatric eye care. It is crucial to understand that duration of eye care differs immensely between adults and children. An adult might need a month for recuperation post a cataract surgery. In children, it calls for lifetime care.

> *"Awareness has to be created among all, what we call the three Ps, the public, the professionals and the policy makers."*
>
> – **DR. GULLAPALLI N RAO**
> Academician,
> Ophthalmologist, LV
> Prasad Eye Institute

Most parents are reluctant to initiate treatment of their children post diagnosis of condition like refractive error in the hope that it would be cured in due course of time. In a study on caretaker awareness, Nirmalan, K. P et al. (2004) found many misconceptions among the respondents such as; children under 4 years should not wear spectacles, strabismus is untreatable, it does not lead to vision loss but is a sign of good luck, etc. It was also found that people approached ophthalmologists as a last resort after consulting traditional healers and general physicians. A study on childhood blindness among school children in Andhra Pradesh showed that close to 30% of the parents of the blind children had not approached an eye care center owing to lack of awareness, and that 46% of parents did not approach pediatric eye care centers due to lack of availability (S. Krishniah et al., 2012).

Development delays are not highlighted enough among child eye health problems. Parents need to follow their children's milestones, and need to take them for regular eye check-ups as there are chances of vertical vision impairment or cerebral vision impairment owing to brain development issues. For instance, if a child is born prematurely or weighs less than 200 grams, screening at least once in three months is a must, to rule out conditions like Retinopathy of Prematurity (RoP). Most parents are unaware that a pre-term baby may have a higher risk of RoP. This awareness is found lacking even among the literate and financially

sound population. Due to lack of awareness, facilities for eye care in government hospitals are seldom being availed, even when they are available. Thus, increasing awareness is necessary among general population, government officials and policy makers who would take notice, thereby working towards including the eye health component in the national or state specific child health programs.

Lack of Access For Socio-Economic Deprived Sections

While government programs like *Ayushman Bharat* provide facilities for accessible healthcare, the cost incurred for pediatric ophthalmology is still higher. The services, resources and equipment needed to perform a surgery on adults is much less than that of children. There is a need to effectively convince the family that while it requires large investments, the returns on child eye care are long term and multi-fold. However, unless supported by government or other service providers, healthcare will remain inaccessible.

> *"You need $20 to perform an adult cataract surgery; you will need a minimum of $250 to conduct a quality cataract surgery on a child."*
>
> – **DR. RISHI RAJ BORAH**
> Country Director,
> Orbis India

For succeeding in community-based care models and to reach out to children of all ages, it is essential to target the *Anganwadi* centers and local level frontline workers such as ASHAs. There is a need to make healthcare a requirement that is affordable and accessible.

Misconceptions and Myths Surrounding Eye Health

There are some misconceptions at the community level, with family members often discouraging the use of glasses at an early age. Owing to lack of awareness, parents may not realise that the first few years are crucial for the development of the eyes, and that without spectacles, a child might become visually impaired. Another belief is that marriage prospects, more so for the girls, will be affected by the use of spectacles.

Interaction with experts in the course of this research revealed that some parents hesitate to bring their children for an eye check-up. They hold the misconception that their child is bound to be healthy since neither of the parents have any vision problems. Another misconception is that if the child starts a healthy diet after diagnosis, there will be no serious eye ailments or further complications. Studies on spectacle compliance shows that there are issues like peer pressure and fear of being ridiculed by relatives.

Another belief is around the use of natural remedies to address the problem of refractive error. When that fails, parents may bring their child to an ophthalmologist. But by then, considerable time is lost, which adds to the problem of vision. Parents tend to get anxious if their child is diagnosed with color vision deficiency. Treatment of vision problems like strabismus is postponed or delayed (such as just prior to marriage) resulting in complications.

Supply Side

Infrastructure Issues

Interactions with experts revealed that country level data points towards the fact that less than 10% of the population of rural India use modern healthcare and usually rely on traditional practitioners. This situation will prevail unless adequate steps are taken to expand the reach of services in relation to primary healthcare, and to strengthen secondary and tertiary eye care.

Eye care hospitals can be divided as primary, secondary and tertiary centers. Secondary hospitals mainly deal with cataract surgeries, refractive errors and select pediatric cases,

which are different from adult eye healthcare. Primary care hospitals usually refer cases to secondary or tertiary eye care institutes. Additional focus should be given to tertiary care, which deals with complex cases like retinal detachment or eye injuries. There are hardly any dedicated wards or Eye OPDs for children, apart from those in Centers of Excellence. Eye healthcare is worse in rural areas. Institutes like All India Institute of Medical Sciences (AIIMS) cater to patients from remote parts of the country. This is mostly undertaken for eye problems that could have been easily treated in the local health centers or facilities in other regions. Information from the expert interviews in this research revealed that most of the sophisticated eye treatment equipment cost anywhere between INR 20,00000-30,00000, with high maintenance costs attached to them. Fibre optic cables alone cost

INR 80,000 – 90,000. All this is in addition to various training needs, laser and other advanced treatment options.

Some efforts from the government for healthcare are Rashtriya Bal Swasthya Karyakram which are especially targeted programs for children's health and development, but are not inclusive of eye health. There needs to be a balance between both so that if the service is unavailable in the public sector, it can be availed from private sector service providers, under various government schemes like *Ayushman Bharat*.

Lack of Specialised Human Resources for Pediatric Eye Healthcare

Pediatric eye care requires more of trained human resources. The medical practitioners need to be oriented in pediatric refraction. This poses challenges, as there is a dearth of training programs to build capacities of pediatric ophthalmologists. There is also a shortage of trained pediatric nurses and pediatric anaesthesiologists with expertise in pediatric eye care. There are inadequate trained resources in India to perform refraction screening, preoperative care and routine diagnostic tests. Added to this, there is an inequitable distribution of eye surgeons – 1: 20,000 in urban areas to 1 in 2,50,000 in rural areas.[22]

Lower financial prospects of pediatric ophthalmology also discourage many medical professionals to opt for it, leaving the majority of such treatments to be restricted to a few institutes. Since individual professionals cannot sustain themselves financially with pediatric care alone, they try to balance it by expanding their services to adults. One of the experts interviewed as part of this study mentioned that glaucoma specialists

22 Rao, G.V., Issues in eye care in India. India Country Director, ORBIS International

are usually involved more in management of adult glaucoma and lack awareness about pediatric glaucoma. Lack of pediatric glaucoma treatment centers in India adds to the problem. There is a need for more awareness amongst glaucoma specialists and pediatric ophthalmologists so as to identify the condition and refer the patient to a tertiary institute where treatment facilities are available.

Lack of Training or Skill-Sets to Address Child Eye Health Issues

The inadequate number of pediatric ophthalmologists hinder quality eye care services in India (Nirmalan et al., 2004). A significant number of hospitals in the country have specialty-trained or specialty-oriented ophthalmologists, but lack a trained pediatric team. According to Family Health and Development Research Service Foundation (2007), about half of the ophthalmologists are surgically inactive within the country.

One of the experts interviewed as part of the research, Dr. Suma Ganesh, Deputy Medical Director, Chairperson and Head of Paediatric Ophthalmology and Strabismus, Dr. Shroff's Charity Eye hospital argued that it is important to train pediatricians as they who can detect eye problems in children. She also opined that they should be made to undergo training to identify and treat common eye problems like cataract and RoP and be knowledgeable about the protocols and guidelines for treatment and referral. The necessity for antenatal check-ups should be made available for neonatologists and gynecologists.

> *"The main gap is that there is no clear understanding on whose ownership is child's vision and eye health. Is the child's eye health the ownership of the pediatrician or is it the ownership of the ophthalmologist?"*
>
> – **DR. SUBHADRA JALALI**, Faculty and Head, Department of Retina, LV Prasad Eye Institute

Lack of Coordination Between Gynecologists, Pediatricians and Ophthalmologists

In India, matters related to child eye healthcare, such as school screening or new-born eye health comes under the NPCB. However, NPCB focuses more on adult eye conditions, and this focus needs to branch out to children's eye care. Currently, children's specialists are dealing with vaccinations, nutrition and heart disease, but not with eye healthcare. Eye specialists may not be equipped to deal with children. So there remains a gap in establishing accountability for children's eye care.

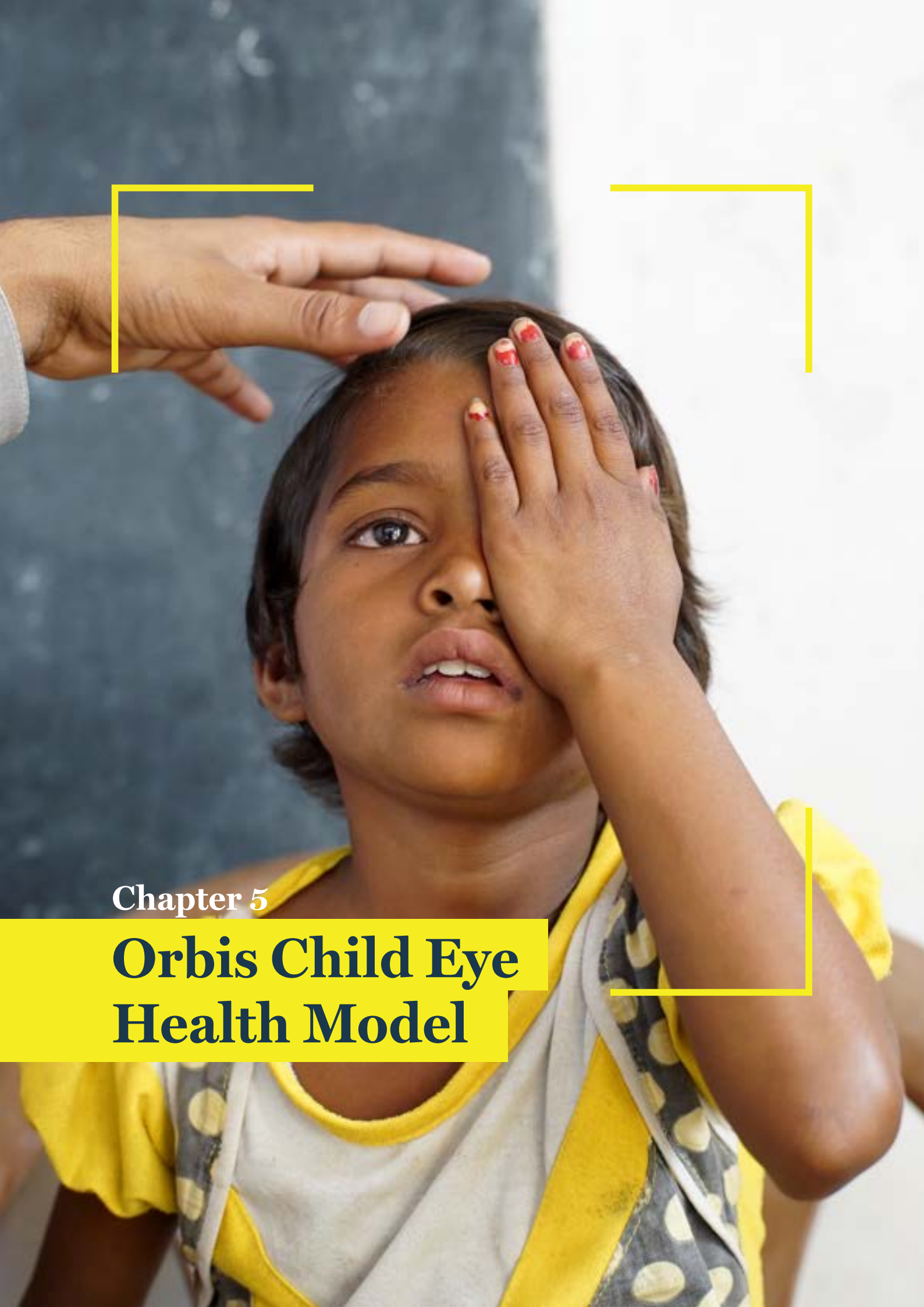
There is a lack of coordination between trained medical personnel and their placement in the required primary health centers (PHCs). Since they provide general primary healthcare, specialised eye health professionals at the district level are crucial. Pediatric healthcare requires different skill-sets to identify the disease, as the child may not be able to articulate his/ her condition. Even if there are sufficient pediatric screening services in the PHCs, they might still face a dearth of skilled professionals to enable early detection of childhood vision problems. When a child with multiple disabilities seeks healthcare, he/she is directed to ophthalmologist only if there is a specific problem in eye health. Follow-ups of all the children admitted in NICUs for the visual milestones for two - three years could ensure that other disabilities are detected early.

Pertinent challenges affecting child eye care in the Indian context are as follows:

Social	• Societal Pressures • Gender discrimination • Delay in immediate treatment for infants • Poor socio-economic conditions
Economic	• Poor financial resources • Child eye treatment is more expensive than the same for adults
Parent's Awareness	• Superstitions and taboos around eye health conditions • Lack of awareness about the nutritional deficiency and other causes of poor eye health • Lack of safety and preventive measures for the child by people in general • Taking prenatal and neonatal eye care lightly • Lack of awareness about the need for cleanliness, hygiene, and proper sanitation • Lack of awareness about various eye conditions that can be caused by allergens like pollen
Misconceptions	• Taboos surrounding lazy eye, amblyopic eyes, and strabismus (squint) • Tendency to wrongly relate all eye health conditions to nutritional causes • Reliance on quacks for conditions like red eye • Misconception that eye problems are related to the elderly; that a child should not wear spectacles
Lack of Interest in Accessing Healthcare	• Not adhering to Follow-ups and consequent care for children enrolled in blind schools
Infrastructure	• Lack of specialised equipment, screening mechanism, charts for child eye screening • Existing facilities and specialised medical professionals are expensive and difficult to access • Limited facilities in rural areas • Many secondary and tertiary hospitals do not have pediatric ophthalmology units • Lack of rehabilitative facilities
Human Resources	• Lack of access to healthcare and skilled medical professionals in rural areas • Lack of appropriate skillset and mindset for child eye care • Low remuneration in pediatric eye care

In the western countries with less stigma linked to wearing spectacles and with a structured rehabilitation effort in place, eye healthcare systems are more successful. Collaborative efforts and civil society partnerships in countries like USA, Sweden, Finland, Japan, Singapore and Australia have produced successful results. Eye healthcare and rehabilitation are more advanced in Nordic countries, owing to better technology that improves the mobility of the patients. However, Sri Lanka and Thailand have an effective primary care network and immunization programs, which can provide inputs on improving pediatric eye care in other countries. India, with its intensive skill training has enabled the development of training centers that provide teaching and training in pediatric cosmetology, and have been providing services to people from neighbouring countries like Bangladesh and Pakistan.

An area of improvement in the context of developing countries is to establish a primary action system and referral linkage mechanism. Coupled with community development and awareness initiatives, this can improve the levels of health-seeking behaviour among people. However, in the Indian scenario, door to door screening will be difficult, but personnel in Vision Centers can be trained to identify children with pediatric cataract and glaucoma. In subsequent chapters, prevalent solutions, rehabilitation and areas of improvement will be discussed in detail.



Chapter 5

Orbis Child Eye Health Model

Orbis international, with its presence in over 193 countries, focusses on prevention and treatment of eye diseases among children. Some of the key contributions of Orbis in India are as stated here:

- India Childhood Blindness Initiative is the flagship program of Orbis, which was started in 2002 with the establishment of Dr. Shroff's Charity Eye Hospital in Delhi. The program initially focused on identifying tertiary level eye hospitals where Child Eye Centers could be established. Further, a country-wide survey was undertaken to generate evidence for human resource and infrastructure requirements for elimination of avoidable childhood blindness[23].

- Orbis has successfully established 33 Children's Eye Centers across 17 states in India. The availability of pediatric ophthalmology service care was 1 for 400 million in India in 2000 and with Orbis's contribution it has improved to 1 for 20 million across the country.

- Orbis insists on Knowledge, Attitude and Practice Studies. It has conducted research in their areas of work to assess the gaps in terms of awareness about general eye care, particularly pediatric eye care. Orbis also works with partner hospitals to create pediatric teams who are then trained in the areas of pediatric ophthalmology, pediatric anaesthesia, pediatric counselling. This training is extended to paramedics so the care is made accessible to children who require it.

- Orbis has also partnered with 40 large community eye care centers across the country which have their own pediatric eye centers with low vision departments. Children with low vision are provided with aid. These children are ultimately able to read and write if they learn braille and can explore various career opportunities.

- The REACH (Refractive Error among Children) program functions across 15 districts of India to fight the problem of refractive error. They have also worked in the areas of eye banking, diabetic retinopathy and quality assurance, by developing the Quality Resource Center which supports eye care facilities across India and internationally.

23 http://www.cehjsouthasia.org/article/pediatric-eye-care-team-a-comprehensive-approach/

- Orbis is also the founder member of Vision 2020: The Right to Sight-India.
- Orbis has initiated training programs for doctors, nurses, other eye health professionals, community outreach teams and medical technicians. They also support local hospitals and clinics with infrastructure and systems to provide primary and tertiary care, as well as improve public awareness around eye health. New innovations like digital tele-medicine and tele education platform, Cybersight are among other initiatives which is open to health professionals around the world for training, consultation and research.
- Orbis has pioneered the introduction of pediatric ophthalmology services in rural India and has worked with communities to improve awareness levels.
- Orbis has also contributed to the development of pediatric ophthalmology as a distinct sub-specialty in the Indian ophthalmology landscape.
- Orbis has been instrumental in creating and promoting the idea of a pediatric ophthalmology team consisting of the pediatric ophthalmologist, optometrist/ orthoptist, pediatric anaesthetist, pediatric nurse and other support staff such as pediatric patient counsellors and outreach coordinators. The team is trained to be observant of the nuances of child eye care. This team works in improving the quality of child eye care centers by working with voluntary organizations and eye care institutions.
- To enable wide scale training of the medical personnel, three existing tertiary level pediatric facilities in the country were developed as Pediatric Ophthalmology Learning and Training Centers by providing infrastructural and technical support.
- Orbis also provides fellowships in pediatric ophthalmology, short/long-term training programs, and workshops in the area of eye healthcare.
- Orbis has created more customised hands on opportunities through the Flying Eye Hospital and Hospital Based Trainings to increase the clinical and surgical abilities of eye healthcare providers. These trainings are customised to the needs of the trainee as well as the healthcare context of the community they are serving.

5.1 The Orbis Model for Child Eye Care

Orbis began its flagship program in India through the India Childhood Blindness Initiative (ICBI) in 2002. Orbis has been partnering with hospitals across the country, through ICBI, to develop fully equipped pediatric eye care units, strategically located in the underserved areas.

Composition of an Orbis ICBI Project

An idea team composition consists of:

- Pediatric ophthalmology team
- Trainings-Pediatric Ophthalmology Learning and Training Centers (POLTC), Continued Medical Education (CME) and Hospital Based Trainings (HBT)

Approach: The project is implemented in two phases with quality assurance phase for two years, followed by strengthening service delivery at the Children's Eye Center for next four years.

Preliminary Analysis: Prior to project implementation, the following parameters are analyzed in the project catchment area:

- Epidemiology of childhood blindness
- Quality of clinical care
- Trained manpower and facilities or specialized eye care
- Primary eye care and referral network for children
- Community awareness

Orbis has contributed to the development of pediatric ophthalmology as a distinct sub-specialty in the ophthalmology landscape.

Partner Assessment: Orbis also assesses a prospective partner's capacity to establish Children's Eye Center on attributes ranging from clinical services to human resources and infrastructure to ophthalmic training.

The Program Implementation Cycle is detailed below:

Phase I

Implementation of Quality Management System

During the quality phase, the Quality Resource Center at Dr. Shroff's Charity Eye Hospital (SCEH) supports Orbis partner hospitals in developing a Quality Management System (QMS). A gap assessment is conducted to identify gaps in the current processes and systems at Orbis partner hospitals. Orbis identifies staff and trains them to form a quality assurance team to guide, monitor and support clinical and non-clinical teams in providing quality eye care. This team constitutes of Quality Manager, Safety Officer, Infection Control Nurse and other staff for implementing QMS. Further, a quality policy is developed, and key areas of quality improvement are identified. During the quality phase, Orbis also facilitates capacity building and promotes leadership through modifications in organizational structure, creation of a core quality committee and various quality sub-committees and leadership development activities.

Standard Operating Procedures (SOPs) and manuals are developed and used to orient staff in each department for implementation. Core Quality Committee along with sub-committees are formed to ensure that quality protocols at the partner hospitals are adhered to. Additional modules in the Health Management Information Systems (HMIS) are included to ensure necessary data collection from patient care and manage continuous improvement as a result of QMS implementation.

Infrastructure Support

Quality related structural modifications and resources: Based on the gap assessment done by QRC, Orbis supports partner hospitals in facility improvements in terms of infrastructure and equipment, to address immediate patient safety issues. If there are major structural modifications, adequate resources are also allocated to partners to carry out such modifications.

Phase II

Training

To support the hospital in providing continued pediatric services, a pediatric ophthalmology team is identified and trained at one of the Orbis Pediatric Ophthalmology Learning and Training Centers (POLTCs). The pediatric team consists of:

- Ophthalmologist
- Anaesthetist
- Optometrist
- Three ophthalmic nurses
- Low Vision Expert
- Vision Technicians
- Outreach Coordinator
- Biomedical Technician
- Patient Counselor
- Project Manager
- Hospital Administrator

The training programs are completed by end of the first six months of Phase II to ensure maximum presence of workforce for delivering pediatric services in the hospital.

Pediatric Ophthalmology Team Approach

CLINICAL PERSONNEL
- Ophthalmologist
- Anaesthesiologist
- Ophthalmic technician
- Optometrist/Orthopist
- Ophthalmic nurse
- Operating room technician

NON-CLINICAL PERSONNEL
- Eye care manager/administrator
- Community eye care coordinator
- Medical records in-charge
- Stores/supplies in-charge
- Bio-medical technician
- Patient counselor
- Receptionist
- Optician

SUPPORT SERVICES
- Patient services
- Housekeeping
- Security
- Transport

Continuous Medical Education (CME)

CME in child eye care, and awareness programs on the importance of early referral are organized during training programs for ophthalmologists, general physicians, pediatricians, neonatologists and rural registered medical practitioners (RMPs) in the project catchment districts.

Hospital Based Training programs (HBT)

Hospital Based trainings are conducted at the partner hospitals by Orbis Volunteer Faculty, to enhance the skills of the pediatric team. These HBTs include:

- Training programs in pediatric surgical and treatment procedures
- Hands-on training
- Tailor-made lectures
- CMEs as part of the HBT

Infrastructure Support

Infrastructure support in Phase II from Orbis constitutes:

Primary Eye Care Services: To support the hospital in providing primary eye care services to the community, new vision centers are established and/or existing vision centers are strengthened where required.

Children's Eye Center: Orbis supports its partner hospital in renovating, refurbishing or establishing Children's Eye Centers.

Orbis supports the following facilities in a Children's Eye Center:

- Registration desk
- Child friendly OPD entrance
- Waiting area along with feeding room
- Play area (furnished with toys, books and safe play items)
- Examination room (Ophthalmologist)
- Patient Counselling Section
- Refraction room (Optometrists, Ophthalmic personnel)
- Patient Recovery Room adjacent to the Operation Theatre
- Patient Ward: dedicated for children with a small child-friendly area and nursing station

Service Delivery

- To increase the uptake of pediatric eye care services, the project team conducts screenings in schools and *Anganwadi* Centers in the project catchment area.

- School teachers, *Anganwadi* workers and community volunteers in project catchment area are oriented on preliminary eye screening and referral of children to the base hospital/Vision center based on the need.

- The children identified with refractive error are provided with spectacles while the children identified with other eye conditions that require further treatment/intervention are referred to the base hospital. The spectacles and surgeries for the children supported in the project are free/subsidized.

Vision Van

Orbis supports its partner hospitals with a Vision Van that is well equipped to conduct screening and to dispense spectacles in the community. This improves accessibility and affordability in underserved areas by providing primary eye care services at the doorstep, and reduces loss of wage. Exclusive pediatric camps are conducted to reach out to children with special needs, where necessary. The Vision Van is also used for follow-up of post-operative patients and doubles up as a medium to disseminate eye health information.

Technology

Outreach activities organized through vision centers, community camps and Vision Van are linked to an Orbis IT-enabled data management system, ICOM, interfaced with

the existing HMIS at the partner hospitals to enable easy data flow while also reducing errors. ICOM is a comprehensive software solution which makes outreach initiatives more effective and provides optimal data management for primary eye care services.

The need for ICOM arose as a result of:
- Difficulty in maintaining continuity of care between outreach and fixed facility
- Difficulty in referral management
- Wastage of time and effort in analysis and report generation
- Inadequate monitoring & control mechanisms

Referral

Referral linkages are established by Orbis partner hospital with Neonatal Intensive Care Units (NICUs) at private and government hospitals to improve early referral of children in need of eye care services.

During the project service delivery phase, a referral network is created which consists of:

- School teachers
- *Anganwadi* workers
- Community health volunteers
- Outreach camps
- Referrals through vision centers
- Other stakeholders

Awareness

- To increase community awareness of child eye health and to improve eye health seeking behaviour, one-on-one counseling of patients at all service points (including the base hospital, vision centers, community camps and mobile vision van) is undertaken.

- Additionally, findings from the KAP study, conducted in Phase I of the project, are used to identify gaps in knowledge, attitude and practices related to eye care within the community. Key findings from the study are then used to further create communication materials/tools to be used to generate awareness.

- Audio-visuals posters, group discussions and distribution of leaflets during outreach camps are undertaken through the project; FM radio and TV channels are used for mass communication where possible.

- A post KAP (Knowledge, Attitudes, Practices) study is conducted to understand the improvement in awareness within the community about child eye care.

- Stakeholder engagement at district and state levels is also done by conducting meetings to enhance their participation in delivering pediatric eye care services, generating community awareness and in promoting public-private participation.

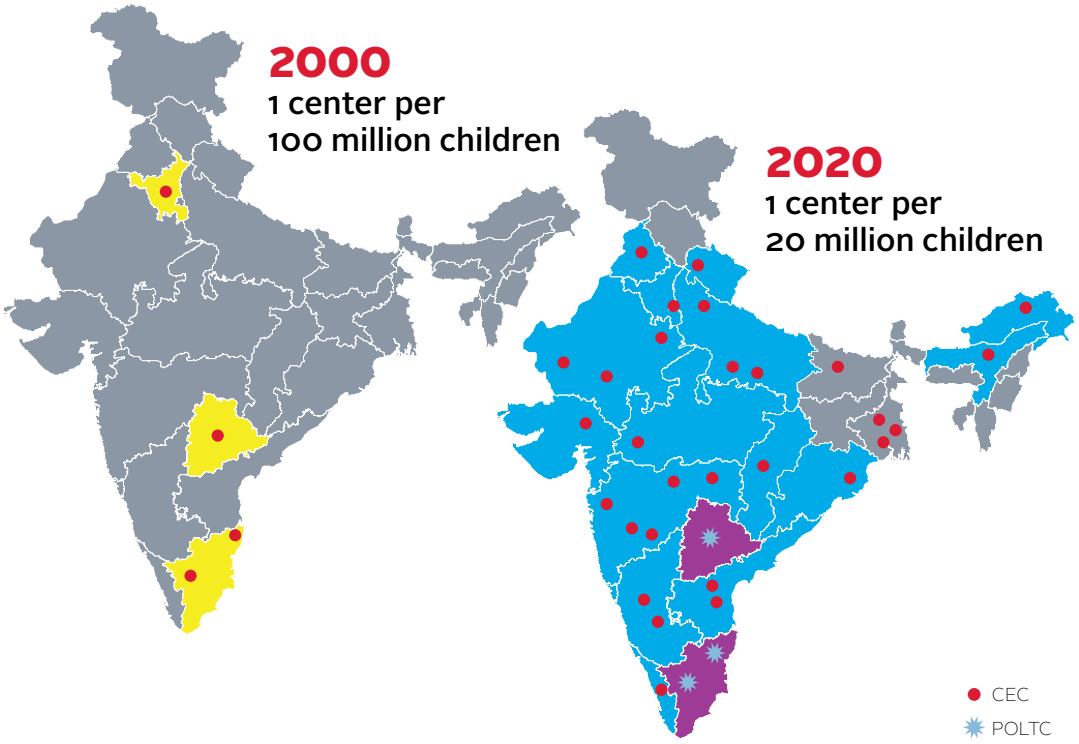
The Orbis CEC Network

The Government of India estimates that for every 10 million people, one pediatric eye care facility is required. In 2000, there were only four comprehensive tertiary pediatric eye care centers in India. At that time, with a population of 1 billion, India needed 100 Children's Eye Centers (CEC) as per the WHO guidelines, with one center per 10 million people.

Today Orbis has established 33 CECs across 17 states in India. The 33rd Center was established in Bihar in April 2019, the state's first such center. This remains the largest national network of CECs in the world and reaches over a million children every year.

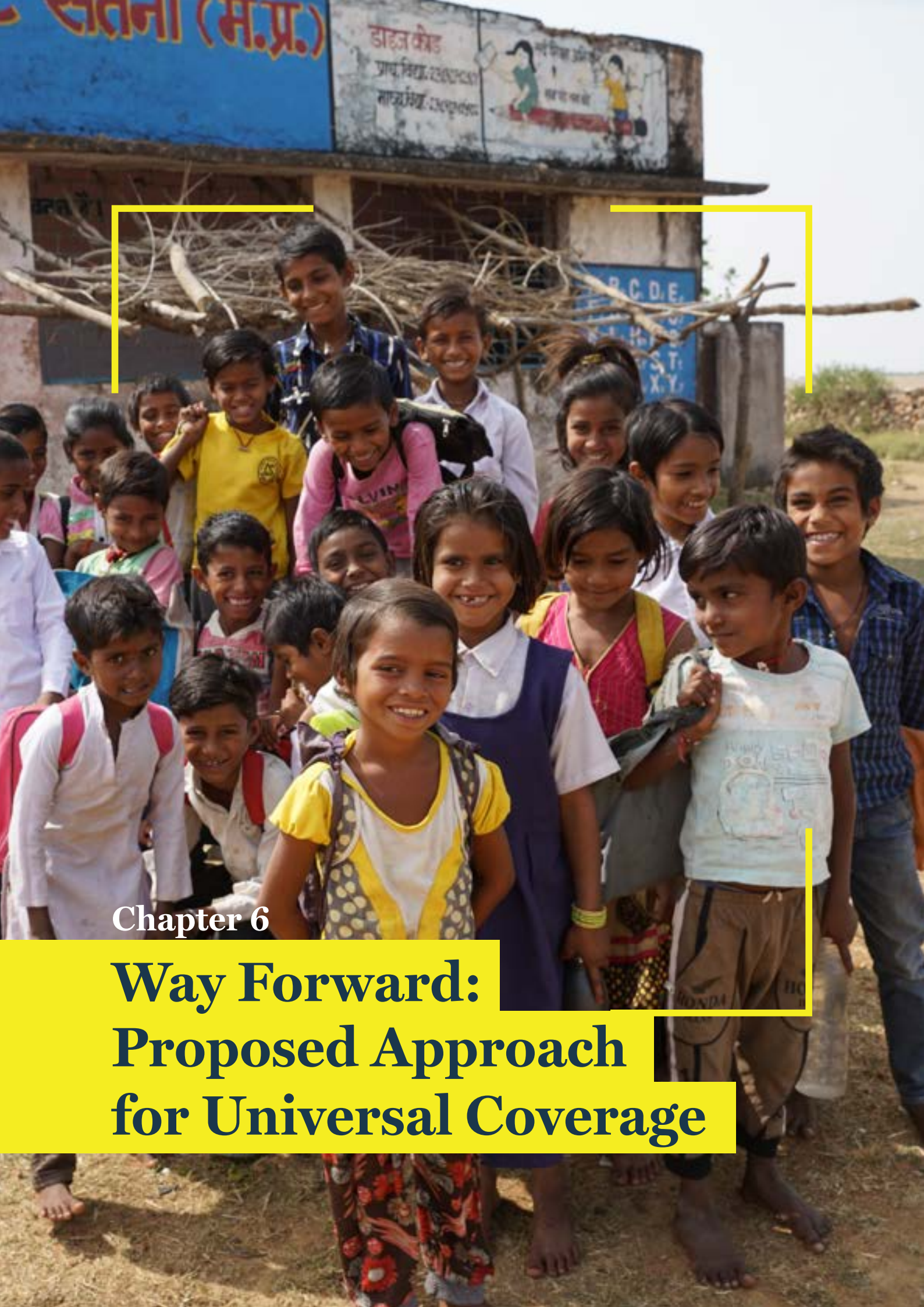
Through the invaluable support of its partner hospitals, Orbis is reaching children in need of care and continues to extend the scope of this network. With almost two decades of contribution in this field, Orbis has become a trusted name within the ophthalmic fraternity and in the community at large, for its efforts to improve child eye health.

INDIA CHILDHOOD BLINDNESS INITIATIVE (ICBI)



List of Children's Eye Centers Established by Orbis

LOCATION	NAME
Udaipur	Alakh Nayan Mandir
Mastichak	Akhand Jyoti Eye Hospital
Bangalore	Bangalore West Lions Super Specialty Eye Hospital
Ludhiana	Christian Medical College and Hospital
Indore	Choithram Netralaya
Moradabad	C.L. Gupta Eye Institute
Dahod	Drashti Netralaya
Delhi	Dr. R.P Centre for Ophthalmic Sciences (AIIMS)
Delhi	Dr. Shroff's Charity Eye Hospital
Aligarh	Gandhi Eye Hospital
Mount Abu	Global Hospital Institute of Ophthalmology
Dehradun	Himalayan Institute Health Trust
Pune	H.V. Desai Eye Hospital
Dhenkanal	Kalinga Eye Hospital and Research Centre
Kanpur	Khairabad Eye Hospital
Maharashtra	Lions NAB Eye Hospital
Angamaly	Little Flower Hospital and Research Centre
Mumbai	Lotus Eye Hospital
Raipur	MGM Eye Institute
Hubli	M. M. Joshi Eye Institute
Itanagar	Ramakrishna Mission Hospital
Kolkata	Regional Institute of Ophthalmology
Guntur	Sankara Eye Hospital
Chitrakoot	Sadguru Netra Chikitsalaya
Anandpur	Sadguru Sankalp Netra Chikitsalaya
Jaipur	Sahai Hospital & Research Centre
Jalna	Shri Ganapati Netralaya
Siliguri	Siliguri Greater Lions Eye Hospital
Kakinada	Srikiran Institute of Ophthalmology
Guwahati	Sri Sankaradeva Nethralaya
Nagpur	Suraj Eye Institute
Kolkata	Susrut Eye Foundation & Research Centre
Haldia & Amtala	Vivekananda Mission Asram-Netra Niramay Niketan



Chapter 6

Way Forward: Proposed Approach for Universal Coverage

This section will discuss the way forward for universal coverage of child eye healthcare in India. It will briefly discuss the impact of COVID-19 on eye healthcare and present a few recommendations to improve eye healthcare in India.

Studies show that a comprehensive eye care approach should be adopted in which the provision of a continuum of health promotion, disease prevention, diagnosis, treatment, and rehabilitation are all included. It should be able to address the full spectrum of eye diseases. It should be integrated within the community at primary, secondary and tertiary levels, within and beyond the health sector.

To tackle current causes of ocular morbidity due to retinal abnormalities, a careful genetic counselling[24] of parents before child birth, especially in the cases of consanguineous marriage. Timely tele-ophthalmology services to diagnose preventable and potentially blinding diseases like RoP should be emphasized to prevent these children from becoming blind in future. (Wadhwani M, Vashist P, Singh SS, Gupta V, Gupta N, Saxena R.,2020).

Preventable cases of blindness can be reduced at the primary level of service delivery through measures such as improved vaccination coverage, including strengthening of the vitamin A supplementation programs that are run by the Government. Treatable cases require specialised pediatric ophthalmology units and need a comprehensive approach in which systems are required for early identification and referral, including provision of low vision aids to children (S, Krishanaiah et al., 2012).

6.1 Impact of COVID-19

The COVID-19 pandemic and the resultant nationwide lockdown imposed on March 2020 has had an impact on the general mental and physical health, and wellbeing of people, especially the underprivileged, marginalised communities, differently-abled people, women and children. Availability and access to healthcare services across the country were adversely affected during the Lockdown. People who were suffering from different ailments could not get treatment as government hospitals were mostly addressing emergency cases. The OPDs were shut on March 24 after the nationwide lockdown was

24 Genetic counseling is the process of advising individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological and familial implications of genetic contributions to disease

announced by the Indian government to contain the outbreak of COVID-19 pandemic. After a gap of three months, the All India Institute of Medical Sciences (AIIMS) decided to open the physical OPD services from June 25. Even in unlock phase, there is a general fear of going to the hospitals, more so if there are COVID wards in it.

Financially, the impact of the pandemic is unprecedented. The GDP growth rate for April–June 2020 dropped to –23.9%, the worst in Indian history. Thousands of people migrated out of major Indian cities, as they became jobless after the lockdown. People's incomes also took a dip, and vast sections of the population are undergoing a financial crunch. This has had a bearing on people's spending capacities. There were media reports circulating on how certain hospitals were charging exorbitantly for general as well as COVID related treatment. A few instances of people being denied treatment despite their ability to pay, have also surfaced. All these factors, coupled with the fear of getting infected during a hospital visit, is keeping many people away from eye health services.

Mentioned below are some of the consequences on child eye health owing to COVID-19:

- With the advent of online classes, children are exposed to gadgets; their eyes get tired; outdoor activities and social interaction have both reduced.
- Children who have undergone surgery have missed follow-ups because of the unavailability of transportation.
- Treatment and screenings of all eye conditions were delayed, as eye hospitals were only offering emergency services, following the guidelines issued by the Government of India.

- In many areas, doctors had shut down clinics, and there were very few centers providing screening services during lockdown. This especially affected neonatal cases in which treatment should be provided within a couple of hours or days from birth.

Conditions were critical for patients of retinoblastoma and RoP. Dr. Subhadra Jalali, Faculty and Head, Department of Retina, LV Prasad Eye Institute cited an instance wherein a father whose child was suffering from severe eye-ailment took to social media to ask for help with transportation from Cochin to Hyderabad for treatment. The Chief Minister of Kerala intervened and his child was given treatment at the center in Hyderabad.

"Everywhere in the country, during the lockdown the transportation had stopped, people were not allowed to travel. In several hospitals and clinics, doctors were unavailable. We were one of the few centers which were open, we were screening and treating patients throughout the duration of the lockdown. We operated on more than 100 children and we have the data for that."

– **DR. SUBHADRA JALALI**, Faculty and Head,
Department of Retina, LV Prasad Eye Institute

6.2 Suggestions for Improving Eye Healthcare in India

More Investment in Awareness and Publicity Campaigns

Vaseem K, Baig VN, Rai P, Swarnkar M. (2015) argued that the burden of preventable blindness can be reduced to a great extent by increasing the level of knowledge and awareness of common eye diseases so that people seek timely eye care. There should be steps taken to ensure awareness in the community. Awareness initiatives should also address some of the beliefs and myths around eyecare in children, and tackle gender norms that affect the effective implementation of eye care.

There is a general lack of awareness about available national, state level or community level eyecare programs across the country. A nationwide program and campaign to eliminate Polio in India, driven by the Ministry of Health and Family welfare was successful. A campaign driven by the government has the reach and resources to spread the message and drive behaviour change which is unlike possible outreach by any hospital / institute driven local campaigns. As a result of the Polio campaign (the famous message of 'Do Boond Zindagi Ke'), individuals even in remote areas demanded the vaccine for their children. If the same efforts are made for children's eye healthcare by raising awareness through media publicity, it should result in a significant positive impact on eye health.

Need for Making Preventive Model Essential

More importance needs to be given to the preventive model since it helps not just to address the problem of economic burden of childhood blindness, but also takes into account ways to improve the quality of life of the affected. In the preventative model, all stakeholders are educated about simple lifestyle changes that can be incorporated. Some initiatives driven by communities and schools such as; shortening the duration of online classes, providing children with hourly breaks, ensuring adequate outdoor activity,

and minimizing use of gadgets, can have a lasting impact on eye health. This needs to be integrated with the public health model which advocates for a collaborative networking of healthcare professionals to understand the impact of nutrition, overall lifestyle and genetics on children's eye health. Improving coverage rates of immunization, introduction of the rubella vaccine, provision of quality antenatal care and attention to nutrition, will have an even bigger impact on childhood blindness (Gudlavalleti and Venkata, 2017).

Interlinkage of Referral Among Health Personnel – Doctors, Therapists, Nursing Staff, ASHA and *Anganwadi* Workers

A multidisciplinary approach coordinated by an ophthalmologist is needed to manage the underlying causes of visual impairment and to optimize the child's development and social inclusion (Gudlavalleti and Venkata, 2017). Systems should be in place to assure optimum utilization of all resources – funding, infrastructure, equipment and personnel. Intensive training should be provided to eye professionals of all cadres. To ensure community level healthcare, strengthening the skill sets of health workers becomes crucial. They can assist in timely detection, reporting of neonatal cases, referring them to respective hospitals and in creating awareness in the community. A pediatrician or a gynaecologist is the primary contact for health delivery for most children, and diseases that occur at birth, like RoP, congenital cataract, ophthalmia neonatorum, conjunctivitis or a congenital blue deformity can be reported by the pediatrician and gynaecologist. Thus, a cross referral system must be in place. This linkage mechanism is currently not well developed. Hence, the involvement of pediatricians in eye care programs must be increased, and proper protocols must be followed in the referral linkage mechanism.

Higher Focus on Refractive Error

In the next five years a larger percentage of children are estimated to need eye healthcare because of the rise in myopia. As countries become developed and literacy rates increase, technology penetration improves, and the television and mobile usage of children goes up; we can expect an increase in incidences of refractive error. Efforts must be taken to address genetic diseases in children and provide genetic evaluation, counseling and treatment at lower costs. In their study on tribal areas in Odisha, Reddy, Sandip.et.al (2018) states that this is a bigger challenge in a populous country like

To ensure community level healthcare, strengthening the skill sets of health workers becomes crucial. They can assist in timely detection, reporting of neonatal cases, referring them to respective hospitals and in creating awareness in the community.

India with remote and tribal terrains. They suggest large scale school level screenings, investment on skilled human resource, and the use of technology in objective refraction as viable solutions.

Training of Human Resources and Specialised Team for Eye Care

Dr. Parikshit Gogate (Trustee and Ophthalmologist, Community Eye Care Foundation, Dr. Gogate's Eye Clinic, Pune) believes that the Orbis model of training pediatric ophthalmology teams for all eye conditions, including pediatric cataract has been effective. In this approach, the entire pediatric cataract team is trained. Orbis also support hospitals by providing infrastructure and better equipment. It also needs to be understood that pediatric cataract is unlike normal cataract and requires special care and expertise.

Need for More Community Level Interventions and Strengthening of Primary Healthcare Systems

Community level interventions have proven to be more effective and they ease the burden on the treatment. Training of local health workers, implementing better awareness and health education activities and provision of manpower at the rural centers play a significant role in community led interventions. Strengthening and stabilising community

level health paves the way for enhanced focus on pediatric services and improved infrastructure at district hospitals. Early detection and referral should be from a pediatrician or a primary care setting. Gudlavalleti and Venkata (2017) in their research on cases of avoidable childhood blindness in India, states that primary healthcare is critical to the reduction of preventable cases of childhood blindness.

Policy Needed for Mandatory Screening of Infants

Studies have shown that blindness due to RoP can be prevented by following an evidence-based screening protocol, detecting RoP at the pre-threshold stage and providing time-bound treatment (Gudlavalleti and Venkata, 2017). Most school level eye health screenings are for children above the age of 6 years, which gives only a small window to treat conditions like amblyopia. There needs to be screening when a child is around 3 years old, before pre-school or at *Anganwadi* Centers. There is also a need for policy advocacy that RoP screenings must be mandatory for every child who is born preterm and weighs less than 2 kg. The RBSK manual mandates that every neonatologist or pediatrician must refer children at least once to a pediatric ophthalmologist or retina specialist. If RoP screening is made mandatory in every NICU by government centers, it will lead to private centers following the same path.

"So, the first dream is that, at least in these 700 government centers, every child should undergo RoP screening all over the country. If the government does this, then the private practitioners will do it on their own."

– **DR. SUBHADRA JALALI**, Faculty and Head,
Department of Retina, LV Prasad Eye Institute

Expansion of Healthcare – Hub and Spoke Model Involving Technological Advancements

Neonatal eye healthcare can involve multiple models. Given the prevailing constraints in India, incorporating technological innovation in expanding access to care is a more feasible solution. One involves the eye health specialist examining babies in different NICUs within 20-30 days of the child's birth. This model does not wait for the child to be taken to an eye hospital, since data points out that eye hospital based programs may not always succeed. In child center based programs, they can also introduce camera based screenings, where a technician or a nurse can be trained to go in with the camera and take pictures and conduct a tele-consultation with the patient.

Dr. Shroff's Charity Eye Hospital follows a mixed model in their Odisha and Vijayawada centers. Their doctors go to both high target centers and low target centers with low population. They also send a technician with a camera. However, many peripheral health centers do not have the know-how to take care of the children's needs. Especially in the current situation of COVID-19, it is even more necessary to have backups. Citing their experience during the COVID-19 lockdown, Dr. Kasturi Bhattacharjee, Director, Clinics and Academics of Sri Sankaradeva Nethralaya stated that their trained local doctors undertook the screening and they did not have to send anybody from their organization.

Ensuring Continuum of Eye Healthcare Through Follow-ups

Even with timely detection, treatment for vision problems can only succeed with regular follow-ups. For conditions like RoP, the basic model requires the health worker to follow-up every three weeks to six months. With the child growing older, they are referred to the District Early Intervention Center (DEIC) for eye power check-up. Subsequently, eye healthcare is linked with school screenings. There is an expected and needed continuum of care for children until they are old enough to communicate their eye problems. Long term counseling is also needed to encourage children to continue wearing spectacles, explaining to them the benefits of wearing them and the consequences of not wearing them on their eye health.

Given the prevailing constraints in India, incorporating technological innovation in expanding access to care is a more feasible solution.

Streamlined Efforts from NGOs and Civil Society

International non-profit organizations with a wide reach like Orbis, can take on one State and set up a model eye care program for the State, in collaboration with government and private institutions. This would involve their contribution towards different aspects such as creation of information education and communication (IEC) material and assistance in training efforts to fill the gaps of current eye healthcare in the country. It would involve incorporating concepts relating to basic ophthalmology in the curriculum of medical education within different sub-disciplines and specializations. NGOs can organize a national conclave of all the heads of societies and brainstorm on the way forward. Orbis is dedicated to pediatric eyecare and promotes awareness about eye care problems. Institutions like Sankara Nethralaya already support primary and secondary eye care centers. Therefore, collective action with a focus on children's eye health would be fruitful.

6.3 Way Forward for Orbis

Three key priorities for Orbis-5-year vision planning are:

Infrastructure Development

- Expand & Strengthen Orbis's Work on Quality Eye Health Services
- Replicate & Scale-up the Children's Eye Health, Quality Assurance and Refractive Error Among Children (REACH) programs
- In terms of disease control, develop & implement strategies for Retinopathy of Prematurity (RoP) and Juvenile Diabetes. Increasing prevalence & incidence of diabetes has led to increased risk of diabetic retinopathy, but facilities available to address it are limited. With 33 CECs across the country, there is an opportunity for detection and treatment of RoP.
- Orbis India has so far strengthened facilities at tertiary level. As there is a lack of basic pediatric eye care services at primary level, Orbis plans to create sustainable and scalable service delivery models at primary and secondary care facilities for more penetration.

Human Resource Development

- Develop and Strengthen Innovative Training and Capacity Building Models and Approaches

- According to National RAAB survey 2019, 7.25% of blindness caused is due to surgical complications. Currently there are no dedicated simulation centers pertaining to pediatric ophthalmology in India. Simulation technology can help build surgeon competencies, before operating on patients directly, reducing potential risks & promoting safe surgeries. So Orbis intends to promote Simulation in Eye Health by establishing Ophthalmic Simulation Centers and create cadre of trainers in ophthalmic simulation.

- Leverage Cybersight platform to build capacities of HR in eye health through innovative training models. With limited access to training facilities/experts, Cybersight provides a cost effective and time efficient training opportunity.

- Currently, all regions do not have access to quality health training. Orbis India plans to strengthen Regional Resource Centers by improving the Ophthalmic and Para-ophthalmic education and research capacities.

- Promote Competency-Based Assessment Rubrics for better training and learning outcomes.

Leverage Technology, Collaborations and Evidence-Based Research for Effective Eye Care Programs

- There is a lack of affordable, robust, data management systems. So, the Orbis plan includes deploying appropriate, cost-effective technology solutions and leveraging telemedicine platforms to continue training programs.

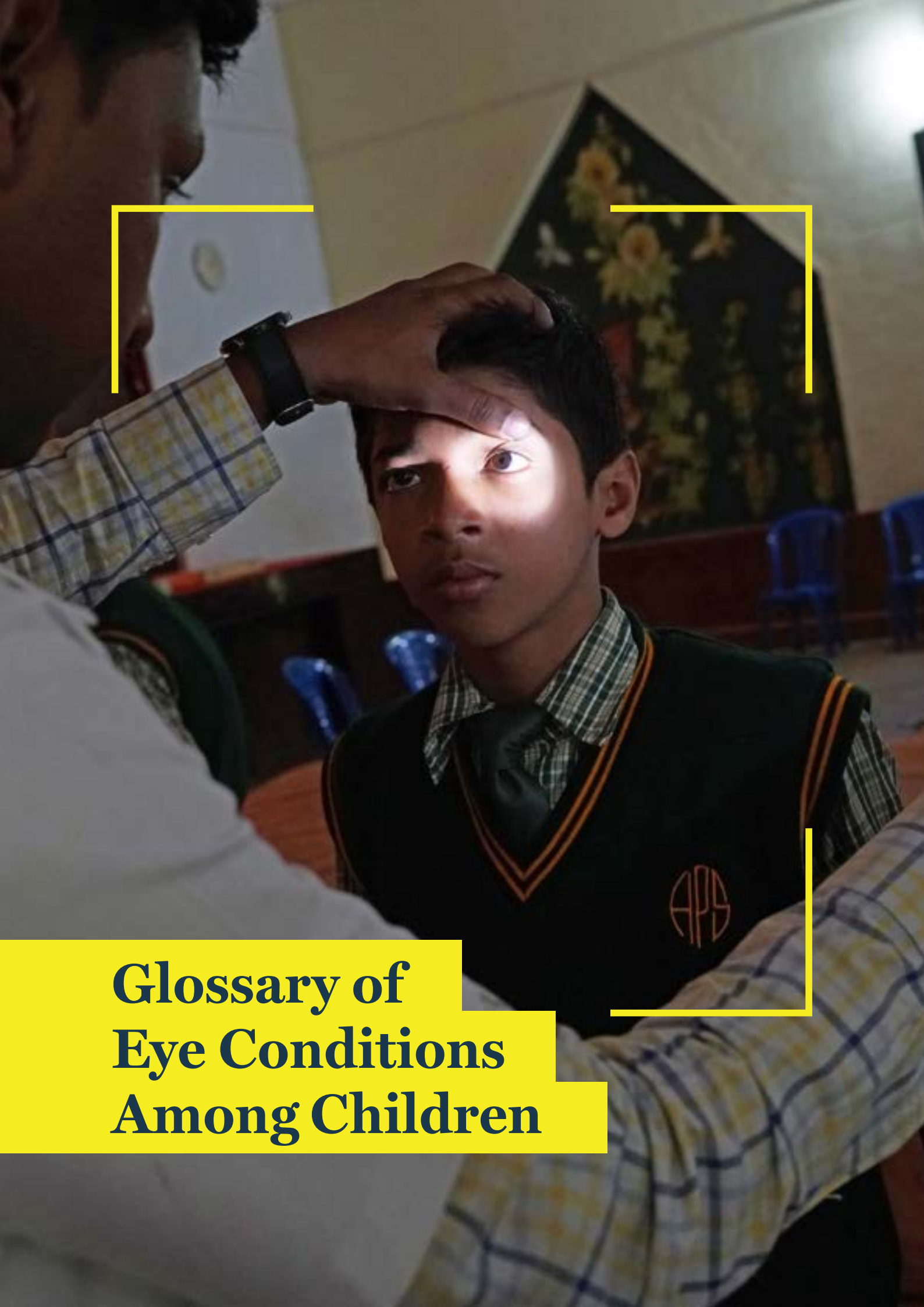
- Currently there is inadequate data to understand community needs, identify best practices and improve impact measurement; Orbis intends to strengthen research initiatives to create evidences that support effective and efficient management of eye health programs.

- Build cross-sectoral collaborations with allied stakeholders, especially reaching out to vulnerable groups.

- Conduct a study on human resources and infrastructure for child eye care in India.

- In terms of Eye Health Promotion and Advocacy, a large data set acquired from Orbis's work in refractive error among children in India can be used to drive policy decisions.

Orbis intends to promote Simulation in Eye Health by establishing Ophthalmic Simulation Centers and create cadre of trainers in ophthalmic simulation.



Glossary of Eye Conditions Among Children

Amblyopia (Lazy Eye)

WHAT IT IS When one eye functions normally but the other does not, the brain pays attention to the normal eye and ignores the eye that is not working properly. This condition is called Amblyopia or "lazy eye". Amblyopia can be caused by any eye problem that blocks or distorts the light passing from the eye to the brain.

SYMPTOMS Common symptoms of amblyopia are blurred vision, blinking of eyes, squinting of one eye and white reflex in one eye. It can set in as early as 4-6 months after birth if there are prior existing conditions of cataract and glaucoma.

CAUSES Mostly hereditary and environmental.

IS IT CURABLE? Yes. Amblyopia is curable if detected before 8 years of age. Follow-up is needed for every 3 months till visual acuity is equal in both eyes and squint alternation is complete.

OTHER IMPORTANT CONSIDERATIONS Pediatricians and neonatologists need to be aligned with eye healthcare for better management of the condition. A common barrier in the treatment of Amblyopia is the hesitation to wear glasses. Preventive approach includes more awareness and education initiatives, and more school and community level screenings. Psychological and social rehabilitation is necessary. While India is fully equipped to handle amblyopia, early diagnosis and screening are needed.

Conjunctivitis

WHAT IT IS Conjunctivitis, also known as 'red eye' is an inflammation of the conjunctiva, the thin clear tissue that covers the white part of the eye and the lines on the inside of the eyelid.

SYMPTOMS Symptoms include itching, watering of the eye and sometimes a sticky yellow crust. Conjunctivitis in new-borns is often transmitted at birth by a mother infected with gonorrhoea and is a potentially blinding disease. Conjunctivitis can also be associated with trachoma in areas where the disease is found.

CAUSES Multiple factors – an infection, allergy, injury or irritation from dust or chemicals.

IS IT CURABLE? Yes. Treatment for conjunctivitis is, eye drops or ointment to either treat or reduce the inflammation. However, if conjunctivitis is caused by an allergy, anti-allergic medications may be given.

OTHER IMPORTANT CONSIDERATIONS

There are different types of conjunctivitis depending on the specific cause of the inflammation, namely, viral, bacterial and allergic conjunctivitis. In excessively polluted cities, cases of allergic conjunctivitis among children tend to be higher.

Childhood Cataract

WHAT IT IS Cataract is defined as any opacity of the crystalline lens of the eye, which impedes image clarity, causing reduced visual acuity and impaired contrast sensitivity. Cataract can occur in one or both eyes and infants can be born with cataracts.

SYMPTOMS There are no early symptoms for cataract. In later stages people report reduced vision and there is appearance of white spot in the pupil.

CAUSES It is mainly caused by hereditary factors. It can also be caused from an injury or trauma to the eye. Lack of nutrition can cause hypocalcaemia[25] and that can lead to cataract.

25 A condition in which the blood has too little calcium. Hypocalcaemia also is caused by lack of vitamin D.

IS IT CURABLE? Yes. In the early stages, cataract may have little effect on the vision, but is potentially blinding in the later stages. To prevent permanent poor vision or blindness, children who are born with cataract must be treated within the first few months. Research in visual neuroscience show that children who have been blind since early life due to cataracts or other conditions, will not be able to gain functional vision if treated late in childhood.[26]

OTHER IMPORTANT CONSIDERATIONS Pediatricians need to be involved in ensuring early diagnosis and referral. In some cases, retinoblastoma (Explained ahead in this section) may mimic cataract. Cataract requires proper vision care and prescription of glasses. India is fairly equipped in dealing with cataract and there are a few centers across the country. Current treatment strategy involves early diagnosis and surgical intervention.[27]

"Pediatric cataracts were also one among the reasons for which a referral is made and this was almost about 1-2% of the overall referrals."

– **DR. JAMEEL RIZWANA HUSSAINUDEEN**, Head, Binocular Vision/Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic, Sankara Nethralaya

"Earlier there was a time when we would admit children for 7 days, 10 days. Now many a times, children come in the morning and they can go home in the afternoon or evening because anaesthesia has become so much safer and better."

– **DR. PARIKSHIT GOGATE**, HV Desai Eye Hospital

Glaucoma

WHAT IT IS If the opening in eyes that allows the clear liquid to drain is closed, more liquid will remain in the eye, thereby increasing the ocular pressure. Increased pressure can damage the eye and cause reduced vision and then blindness.

SYMPTOMS While there are no initial symptoms for glaucoma, eyes may appear blue and bulging, and the patient may experience pain and blindness in the later stages.

CAUSES Causes for glaucoma are sometimes hereditary, but may often be unknown.

IS IT CURABLE? Not fully curable, but manageable. Early diagnosis and treatment is the current strategy and children may require lifelong follow-ups. Without timely treatment, glaucoma might lead to permanent decrease in vision or blindness especially if it is congenital. Surgery can be done to correct the eye muscles and spectacles may be prescribed.

OTHER IMPORTANT CONSIDERATIONS In case of glaucoma, there are chances of recurrence of the condition, depending on the severity. So, long term follow-ups are

26 Kalia, Amy et al., 2017

27 One of our experts interviewed in the course of this research, Dr. Parikshit Gogate argued that Orbis model of a team approach for paediatric cataract has been effective. In this approach, entire paediatric cataract team is involved. They also make available specific equipment used during paediatric surgery. It needs to be understood that paediatric cataract is unlike normal cataract and requires special care and expertise.

"As far as glaucoma is concerned I think the prevalence is high. It is almost 4.0 to 4.5%. So in OPD suppose you see 100 patients, almost 10% belong to glaucoma in some way or the other, that is, either they are suspects or they have full-fledged glaucoma. So overall the percentage of suspects and glaucoma is pretty high and needs attention"

– **DR. SUNEETA**,
Dr. Shroff's Charity Eye Hospital

recommended for children. Glaucoma can be mistaken for corneal opacity or cataract. Preventive approach would work, which includes more awareness and education initiatives and more school and community level screenings. The child might require psychological and social assistance for rehabilitation.

Strabismus ('Squint')

WHAT IT IS Strabismus can occur in one eye or both eyes. It can occur in children before the age of six years, or in some cases, later.

SYMPTOMS Crossed eyes, double vision, head posture (tilting of head to one side), uncoordinated eye movement.

CAUSES Children are prone to strabismus from 4-6 months of age and onwards, and the causes are mainly hereditary.

IS IT CURABLE? Yes, if is treated within few years of detection. Treatment includes muscle surgery, vision therapy and prescription eyeglasses.

OTHER IMPORTANT CONSIDERATIONS Children with this condition often develop poor self- image and resultant psychological problems. Some of the common myths associated around this condition is that it is seen as a sign of luck among some communities in India and is believed that it would correct itself over time.

Retinoblastoma (Cancer of the eye)

WHAT IT IS Retinoblastoma is a rare form of cancer that may occur in childhood (typically before the age of five) due to mutations in what is called the Rb gene.[28] Retinoblastoma can even occur during intrauterine life.

SYMPTOMS The most common first sign of retinoblastoma is a visible whiteness in the pupil called "cat's eye reflex" or leukocoria. This unusual whiteness is particularly noticeable in dim light or in photographs taken with a flash. Other signs and symptoms of retinoblastoma include crossed eyes or eyes that do not point in the same direction (strabismus), a change in the color of the colored part of the eye (iris); redness, soreness,

28 RB1 is a tumor suppressor gene, which means that it normally regulates cell growth and stops cells from dividing too rapidly or in an uncontrolled way. Most mutations in the RB1 gene prevent it from making any functional protein, so cells are unable to regulate cell division effectively. As a result, certain cells in the retina divide too fast and causes tumour or cancer

or swelling of the eyelids; and blindness or poor vision in the affected eye or eyes.[29]

CAUSES Causes are hereditary and about 1 out of 3 children with retinoblastoma have a germline mutation of one RBI gene.

IS IT CURABLE? Retinoblastoma is often curable when it is diagnosed early. However, if it is not treated promptly, this cancer can spread beyond the eye to other parts of the body. This advanced form of retinoblastoma can be life-threatening.

OTHER IMPORTANT CONSIDERATIONS Lack of awareness about the treatment, need of enucleation,[30] long term treatment and risk of relapse and mortality commonly affect successful treatment of retinoblastoma. Proper counselling is necessary and physical, psychological as well social rehabilitation is needed. India has a good number of major ophthalmic centers equipped with retinoblastoma treatment facilities. However, considering relatively high incidence in the subcontinent and uneven distribution of healthcare infrastructure, we are still lagging in the desired goal.

Retinopathy of Prematurity (RoP)

WHAT IT IS If a baby is born before 32 weeks, it is possible that the blood vessels in the retina, at the back of the eye are not fully formed, leading to this condition. RoP develops in preterm neonates after birth and is a potentially avoidable cause of vision impairment and blindness.

29 Retinoblastoma is the most common form of ocular cancer which usually occurs in children less than 2 years of age. This is caused by both genetic and sporadic factors and the affected eye can be saved if detected at an early stage. However due to lack of awareness, most cases comes to the doctors at a very late stages. Early detection, public awareness about various eye disorders and good counseling of parents are the essential steps.

30 The surgical removal of an eye which is usually done under drastic circumstances such as to remove a tumor in the eye or to relieve intolerable pain in a blind eye

SYMPTOMS There are no major symptoms for Retinopathy of Prematurity (RoP) and hence universal screening is important.

CAUSES Premature birth is the cause of the condition, and every child born at less than 34-35 weeks of gestational age is at high risk in India and other middle and low income countries. Minimum age for the condition to set in is 15-20 days after birth.

IS IT CURABLE? In most cases RoP is resolved without treatment but if it gets to an advanced stage with no intervention, it may lead to permanent loss of vision. So, screening and prevention is key to battling this condition.

Primary prevention includes the following:

- Antenatal steroids to high risk mothers.
- Improved quality of labor room practices (first golden hour of birth).[31]
- Improved quality of nursing and medical care.

31 First golden hour of birth is considered crucial for bonding between mother and child, it also includes breastfeeding and it is the transition for the new-born from an internal to external environment

"So color blindness runs in families, that is the only thing. Acquired color vision deficiency is because of many issues including toxicity due to chemicals, due to drugs, exposure to gaseous toxic fumes, exposure to petrochemical agents or alcohol toxicity and things like that."

– **DR. JAMEEL RIZWANA HUSSAINUDEEN**
Head, Binocular Vision/ Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic, Sankara Nethralaya

OTHER IMPORTANT CONSIDERATIONS The common misconception about this condition is that the child might not have any problems since their eyes appear normal. Although this condition cannot be completely prevented, a high quality antenatal and labor room, and neonatal care practices can substantially reduce prevalence and severity of RoP. After the first screening, babies need close follow-up every 1-2 weeks till the retina matures. Usually between stages 2 and 3, most cases can be completely cured. In advanced stage 3 and beyond, the success rates progressively reduce. At stage 5 they are incurable and only palliative surgery provides minimal vision.

Color Vision Deficiency

WHAT IT IS Color vision deficiency is the condition and color blindness, contrary to what is popularly known, is not technically appropriate. Achromatopsia is a very rare form of color vision deficiency vision when a person is totally visually impaired in terms of color. Majority of the cases are due to red-green color vision defects. Blue-yellow defect is seen in less frequency. Patients having red-green blindness cannot differentiate between red, yellow, and green, and those with blue-yellow blindness cannot differentiate between shades of blue and green.[32]

SYMPTOMS Inability to identify and differentiate certain colors.

CAUSES Mostly hereditary but sometimes lifestyle related (Acquired color vision deficiency) caused by exposure to toxic materials.

IS IT CURABLE? Currently there is no complete treatment available for this condition.[33]

32 Verma, C., Paliwal, P., & Singh, K. 2018
33 Sankara Nethralaya in its school screening program found that 2.76% of boys who were surveyed had color blindness. Color blindness affects the quality of life, as those affected are rejected from applying for certain professions.

Refractive Error

WHAT IT IS Refractive errors mean that the shape of one's eye does not bend light correctly, resulting in a blurred image. Main types of refractive errors are myopia, hyperopia, presbyopia, and astigmatism. Researches shows that children often do not complain of defective vision and may not even be aware of their problem. They may adjust to poor vision by strategies such as – changing position in the classroom, moving objects closer, and tending to avoid tasks that require more visual concentration.

SYMPTOMS Blurred or hazy vision, double vision, strained or tired eyes, headache and dizziness.

CAUSES Eyeball length (when the eyeball grows too long or too short); problems with the shape of the cornea (the clear outer layer of the eye); ageing of the lens. Myopia is the most common cause of refractive errors in both children and adults.

IS IT CURABLE? Yes. It needs to be screened and diagnosed, and early intervention is needed usually in the form of glasses. It is recommended to screen children for early detection and intervention to provide them with the best opportunities to learn and develop.[34]

OTHER IMPORTANT CONSIDERATIONS Refractive errors are the commonest causes of visual impairment in children. Recent studies in India indicate that refractive errors were responsible for visual impairment in more than 80% of the children[35] affected. One of the biggest challenges is lack of an effective service delivery mechanism. In addition to a lack of human resources, availability of glasses, and provision of services with accessibility, availability, acceptability and affordability are other challenges. Another area of concern is the lack of awareness within the family and community. This issue particularly stands out in the case of refractive errors when compared to other conditions,[36] because although it is the commonest eye ailment in children, and relatively well known among the masses, awareness is still low.

34 Sheeladevi Sethu et al. (2018)

35 There is significant difference in the academic pressure, lifestyle, socio economic status, gadget use, outdoor activities, difference in lighting levels among various parts of the country and even among private and public schools. With the Orbis Project Sankara Nethralaya has screened over 250000 children over three years and found that the prevalence of refractive errors has moved up from 2 % to 10% in a sample of 1049 schools with private schools reporting as much as 50% in some cases

36 A research by Sethilkumar et al. (2013) throws up a number of interesting insights on parent's awareness levels. Despite the presence of awareness in eye problems in their children, the causes for those problems were not well understood by the parents who were interviewed. Parents considered that unhealthy eating habits and lack of proper nutrition caused ocular disorders, especially refractive error. In addition, watching television, playing video games, and not taking oil bath were perceived by parents as causes of refractive error. Even wearing spectacle is a social stigma, so parents were not in favour of their children wearing it despite being aware of the child's eye problem. One of the important solutions to such problems is to increase the awareness programs, conduct school vision screening programs so that schools can also play a role in seeking eye care for children.

OTHER EYE RELATED ANOMALIES

Some of the other eye related anomalies that are observed in a small portion of the childhood population but which have the potential to lead to visual impairment if not detected and treated at an early stage are:

RETINITIS PIGMENTOSA

Generally, 1/5 persons have a gene mutation causing autosomal recessive RP. However, RP is usually seen in 1 out of 5000 persons and is reported commonly in South India. RP is generally perceived as a feature of Bardet Biedl syndrome, or Usher syndrome (with deafness).

NASOLACRIMAL DUCT OBSTRUCTION

Tears are produced by the lacrimal glands and each time one blinks, tears are spread across the surface of the eye and drain into tiny holes in the corner of the upper and lower eye lids. They then travel through small canals to a sac where the lids are attached to the side of the nose, and then down the nasolacrimal duct. If the duct is blocked, tears cannot drain from the eye and it will collect in the eye. It can be a source of infection. If the obstruction does not open after six months, it may be necessary for a doctor to open them with a simple medical procedure.

JUVENILE RETINOSCHISIS

Juvenile Retinoschisis, also known as X-linked bilateral vitreoretinal dystrophy appears generally early in life and is characterized by vision impairment, and intraretinal cysts in the macula, causing splitting of the retina in a spoke wheel pattern. Female carriers of Juvenile Retinoschisis rarely exhibit abnormality of the fundus.

ANTERIOR SEGMENT DYSGENESIS (ASD)

Anterior Segment Dysgenesis is a spectrum of disorders of the iris, cornea, lens, and trabecular meshwork.

OPTIC ATROPHY

Optic atrophy is usually visible as a mitochondrial disorder. It is usually diagnosed when treating infections like tubercular meningitis, hypoxic ischemic encephalopathy, or degenerative disorders.

PTOSIS

Ptosis is a drooping of the upper eyelid caused by a weakness in the muscle that holds the eyelid. It most often occurs in one eye, but it can also occur in both eyes. It can occur in new-borns or young children. If the vision is blocked, the child may develop amblyopia, and vision may be permanently reduced. This must be corrected immediately. There is no medication or traditional treatments to correct ptosis. The only treatment is surgery to lift the eye lid.

OCULAR MALFORMATIONS (OM)

Ocular Malformations are structural defects of the eye recognizable at birth, arising due to developmental aberrations. The four developmental milestones of the eye are: formation of the optic vesicle, induction of lens, organization of early retina and fusion of the optic fissure. Microphthalmia, anophthalmia and coloboma (MAC) are distinct phenotypes that represent a continuum of structural developmental eye defects.

ACHROMATOPSIA

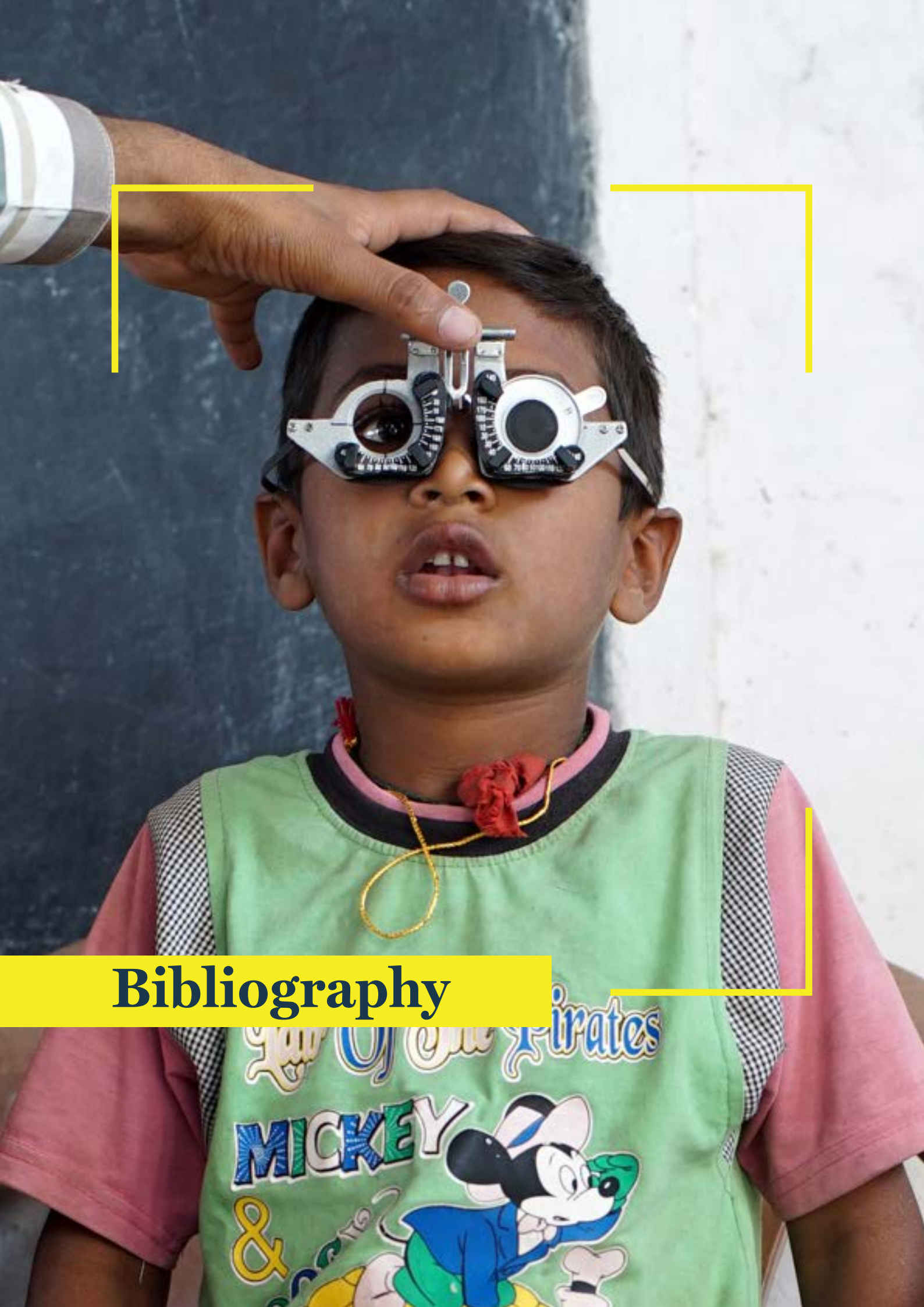
Achromatopsia is an autosomal recessive disorder with partial or total absence of color vision. Persons having total achromatopsia cannot perceive any colors and can differentiate only black, white, and shades of grey. Partial achromatopsia is less severe allowing some color perception. Achromatopsia also manifests an increased sensitivity to light and glare (photophobia), involuntary back-and-forth eye movements (nystagmus), and significantly reduced sharpness of vision (low visual acuity) which are generally developed in the first few months of life. Those with color blindness might not face much difficulty in navigating their daily life, but face rejections while applying for jobs in certain professions later in life. Currently there is no treatment available for this condition.

CONGENITAL HEREDITARY ENDOTHELIAL DYSTROPHIES (CHED)

CHED manifests corneal clouding ranging from a diffused haze to milky appearance of the cornea, with occasional focal gray spots of variable degree. CHED usually results in twice or thrice the increase in thickness of the cornea than normal.

LEBER'S CONGENITAL AMAUROSIS

LCA refers to severe dystrophy of the retina, generally seen in the first year of life with complaints such as nystagmus, sluggish or near-absent pupillary responses, photophobia, high hyperopia, keratoconus, and Franceschetti's oculo-digital sign, comprising eye poking, pressing, and rubbing. Fundus has a variable appearance. Even though in the initial stage, the retina may appear normal, retinitis pigmentosa may usually be observed later in childhood.



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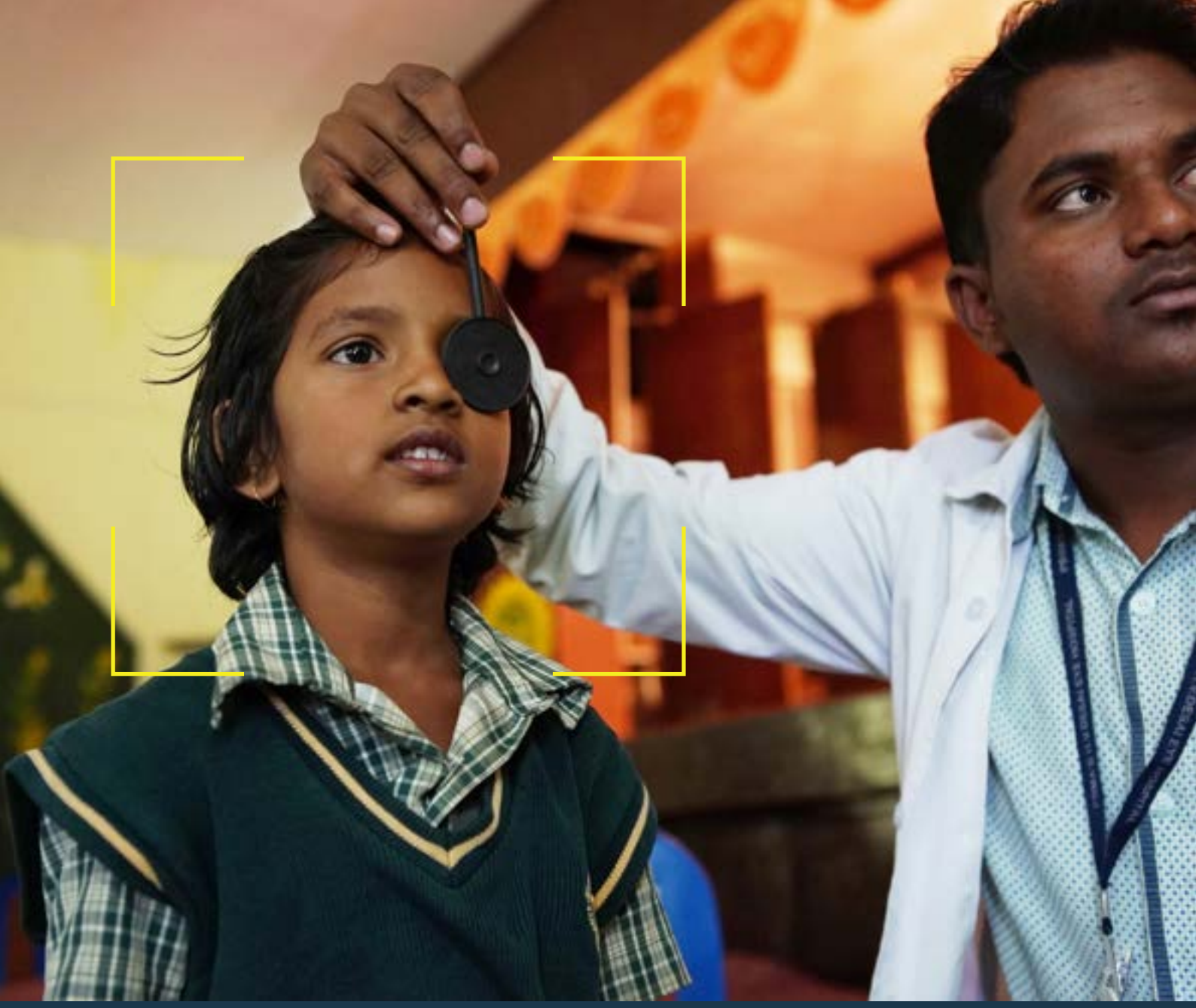
Annexure

List of Experts

Orbis Partner Doctors and Other Leading Experts on Child Eye Care

Name	Designation	Affiliation–Organization	Specialisation/ Primary Focus
Dr. Anuradha Narayan	Principal – Elite School of Optometry Program in Charge – School Children Eye Health – Sankara Nethralaya Vision Screening Coordinator– Elite School of Optometry Clinical Director– Special Olympics	Elite School of Optometry Sankara Nethralaya	School Children Eye Health, Optometric Education, Qualitative Research Health Economics, Optometric Clinical Teaching
Dr. Parikshit Gogate	Trustee and Ophthalmologist	Community Eye Care Foundation, Dr. Gogate's Eye Clinic, Pune	Cataract surgery, Community Eye Health; Pediatric Ophthalmology, Training and Research
Dr. Jameel Rizwana Hussaindeen	Head, Binocular Vision/Vision Therapy, Neuro-Optometry and Amblyopia Care Clinic at Sankara Nethralaya, Chennai Lead Optometrist, QCV–REACH Project	Elite School of Optometry Srimathi Sundari Subramanian Department of Visual Psychophysics Sankara Nethralaya, Units of Medical Research Foundation	Pediatric Optometry, Binocular Vision, Vision Therapy, Neuro-Optometry, Myopia management, School Children Eye Health, Eye Care Research
Dr. Suma Ganesh	Deputy Medical Director, Chairperson and Head of Paediatric Ophthalmology and Strabismus Dr. Shroff's Charity Eye Hospital, Delhi	Dr. Shroff's Charity Eye Hospital, New Delhi, India	Strabismus and Amblyopia
Dr. Suneeta Dubey	Medical Superintendent HoD, Glaucoma and Quality Assurance	Dr. Shroff's Charity Eye Hospital, New Delhi, India	Anterior Segment and Glaucoma Specialist
Dr. Subhadra Jalali	Faculty and Head in the Department of Retina and Faculty in the Children's Eye Care Center at Hyderabad Campus Director of Retina Institute and Director of Quality assurance across the network Director of Newborn Eye Health Alliance (NEHA) across the network hospitals Affiliation: L V Prasad Eye Institute (LVPEI)	LV Prasad Eye Institute (LVPEI)	Retinopathy of Prematurity (RoP)
Dr. Kasturi Bhattacharjee	Director, Clinics and Academics of Sankara Nethralaya (Ophthalmic Oculoplastic & Refractive Surgery department)	Sankara Nethralaya, Assam, India	Retinoblastoma
Dr. Asim Sil	Chief Medical Director	Vivekananda Mission Ashram, Netra Niramay Niketan	Comprehensive Eye care
Dr. Kuldeep Dole	Technical Advisor, Sight first LCIF and Medical Director, HV Desai Eye Hospital	Lion's Club International Foundation PBMA's HV Desai Eye Hospital	Cataract and Medical Retina, Community Ophthalmology

Name	Designation	Affiliation–Organization	Specialisation/ Primary Focus
Anup Zimba	Country Manager	Operation Eyesight Universal	Collaborate with partner eye hospitals in India for capacity building initiatives and infrastructure support. Designing and implementing community-based eye health programs, collaborate with partner eye hospitals in South Asia for capacity building initiatives and infrastructure support
Dr. Gullapalli N Rao	Founder – Chair LV Prasad Eye Institute Chairman of the Academia Ophthalmologica Internationalis	LV Prasad Eye Institute	Corneal disease, eye banking and corneal transplantation, community eye health, eye care policy and planning
Dr. GVS Murthy	Vice President (South), Public Health Foundation of India and Professor, London School of Hygiene and Tropical Medicine First faculty and officer in charge of the Community Ophthalmology Department set up at R.P Centre, AIIMS Director at Indian Institutes of Public Health	Indian Association of Preventive and Social Medicine Indian Public Health Association All India Ophthalmology Society Delhi Ophthalmology Society; Indian Medical Association International Society for Geographical and Epidemiological Ophthalmology Indian Society for Medical Statistics International Agency for Prevention of Blindness Vice President(South), Public Health Foundation of India and Professor, London School of Hygiene and Tropical Medicine in the affiliations	Health Disability, community eye care, control of blindness and visual impairment, epidemiology, public health management, health systems research with special emphasis on disability related issues
Dr. Harsha Bhattacharjee	The Founder, Medical Director and Trustee of Sri Sankaradeva Nethralaya, Northeast India	Sri Sankaradeva Nethralaya (SSN), Assam	Intra-ocular lens implantation, vitreo-retinal care, pediatric eye care, oculoplastic and laser surgery
Dr. P. Vijayalakshmi	The founder members of Aravind Eye Care System and she is the First Resident Medical Officer of Aravind Eye Hospital. The Chief Medical Consultant of Pediatric Ophthalmology & Adult Strabismus clinic and also Chief of Vision Rehabilitation Center at Madurai	Aravind Eye Care System Vision Rehabilitation Center	Pediatric Ophthalmology and Adult Strabismus
Dr. Pradeep Sharma	Professor and Head, Section of Pediatric Ophthalmology, Strabismus, Neuroophthalmology and Oculoplasty	Dr. R.P Centre for Ophthalmic Sciences, All India Institute of Medical Sciences	Pediatric ophthalmology, Strabismus, Neuroophthalmology and Oculoplasty
Dr. Rishi Raj Borah	Country Director, Orbis India	Orbis India	Expertise in strategic planning and implementation of home-grown programs.
Dr. TS Surendran	Vice Chairman, Director Pediatric – Ophthalmology, Sankara Nethralaya	Sankara Nethralaya	Pediatric Ophthalmology and Low Visual Aids & Botulinum Toxin in Blepharospasm and Strabismus



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