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Pictures taken by Andrew Bastawrous  
during fieldwork travels.

**WHO Definitions:**  
**Childhood:** 1-15 years  
**Blindness:**  $<3/60$  in best eye  
or central field  $<10$   
**Visual Impairment:**  $6/18 - 3/60$

## Childhood Blindness: A comprehensive approach to the challenges ahead

A child goes blind every minute. Of the world's 1.4 million blind children at least 50% are needlessly blind.<sup>1</sup> About 1.2 million of the world's blind children live in Africa and Asia. In the poorest parts of the world, up to 60% of blind infants die within one to two years of becoming blind, compared to 10% in the UK and 13% in Sweden.<sup>2</sup> In a population of 10 million there will be 600 blind children in high income countries and 6,000 in very low income countries. This is in part due to the younger age of the population with lower life expectancy in very poor income countries. Poverty, population and poor maternal / newborn health are closely linked to childhood blindness and infant mortality.

Over the last decade attention has increasingly focussed on the long neglected challenge of childhood blindness (CB). It is relatively easy to ignore CB since it only accounts for less than 4% of global blindness (GB). This misleading statistical percentage hides the *real-cost* of CB. Increasingly sophisticated measures have recently been applied to calculate the economic cost and social burden of GB and CB. Approximately 1.4 million blind children worldwide accounts for 70 million blind years (blind years = number of years alive with vision recorded as 'blind') compared to 120 million blind years from the leading cause of world blindness: adult cataract. This makes CB the second leading cause of GB in terms of blind-years. Economic costs of childhood blindness are also significant. Depending on the region, the economic cost varies; a study from India in 1989 estimated a cost of US \$4.4 billion per year from CB for the country.<sup>3</sup> The average number of working years lost with CB is 33 years<sup>3</sup> compared to 10 years due to adult blindness giving the *real-cost* of CB greater than adult cataract blindness.

The approach to CB must match the multifactorial causes of CB. Action at community and rural public health level, tackling poor maternal health wherever present, pre-, peri- and post-natal care. Understanding local practice and customs, and strong advocacy in addition to expert paediatric ophthalmic care for training and building capacity are essential components of a programme. Programmes which do not include a comprehensive approach, especially action that only delivers ophthalmic care, will not be beneficial to children and probably cause more harm than good. Therefore, it is essential for ophthalmologists who actively participate in these programmes to look '*beyond-the-eye*' and determine whether their contribution is practical, effective, sustainable and targets children who need it most.

Causes of blindness in children can be considered as unavoidable preventable and treatable. Unavoidable causes presently include congenital anomalies, retinal dystrophies and brain lesions. At the present time, focus is on avoidable and preventable causes.

## A child goes blind every minute...

Preventable causes of CB are mainly conditions that cause corneal scarring. Others include traumatic cataract, secondary glaucoma and retinopathy of prematurity (ROP). The main causes of corneal scarring are: Vitamin A deficiency, measles, ophthalmia neonatorum and the use of harmful traditional remedies. Children aged 6 to 72 months and females of child-bearing age are most at risk. Vitamin A deficiency is best managed at a public health level. There are currently major disease control programmes in place which are reducing prevalence. Measles is an important cause of corneal scarring, particularly in Africa where there have been multiple epidemics. A very high immunisation coverage rate is required to prevent epidemics of what is a highly infectious virus (see discussion on rubella vaccination later). The most harmful infection in ophthalmia neonatorum is gonococcus (*gonococcus ophthalmia*) which is directly related to rates of gonorrhoea infection. Rates are most prevalent in Africa and Asia. Primary prevention includes sex education, Crede's prophylaxis (cleaning of the eyelids at birth before opening eyes and the instillation of an antibiotic or antiseptic). Harmful traditional eye remedies can cause scarring by a number of mechanisms and a radical change in belief system is required before a shift in attitudes can be achieved that has existed for generations. The training of traditional healers is proving a successful focal point for village treatment and prevention.

Cataract in children is the most common treatable cause of CB and should concern ophthalmic surgeons and multi-disciplinary teams of orthoptists, optometrists and public health personnel. Idiopathic and inherited cataract is common but the incidence of cataract due to rubella and ocular trauma is significantly higher in developing countries.

Rubella cataract is still very common in developing countries due to lack of consistent policies on rubella immunisation.<sup>4</sup> The high frequency of rubella cataract is indicated by a study where the presence of a childhood cataract was a reliable indicator of congenital rubella infection.<sup>5</sup>

Patchy immunisation policies create a greater risk for the non-immunised vulnerable child.<sup>6</sup> Rubella cataract is a rare occurrence in developed nations.

Traumatic cataract in children is a considerable public health problem in developing countries. In population studies, incidence varies from 12 to 33% of childhood

cataracts<sup>7,8,9</sup> although such incidence has decreased significantly over the years in the developed nations.<sup>10</sup> Early detection programmes are necessary to obtain maximum visual benefit from surgery and optical rehabilitation. Teams of paramedical personnel need to be trained by secondary and tertiary eye care centres to cover surrounding rural areas for public education, early detection and referral. Teams are best sourced from the rural areas to be successful and sustainable. These are what I (Arvind Chandna (AC)) term as 'hub and spoke' arrangements where the centre for eye surgery (secondary or tertiary) forms the hub (the central wheel) and rural areas as far as 300 kilometres (the outer circle of the wheel) are covered by paramedical trained personnel forming spokes. They provide advocacy, and public health education for prevention through women's groups and schools, screen for treatable eye conditions. In addition, they provide basic eye care including refraction and spectacles at the local level. They form an important conduit of referral for more serious eye conditions and subsequent follow-up between the rural areas and hospitals at secondary (district) and tertiary level. I have participated and reviewed such programmes and they are the best option for a comprehensive CB programme. Such programmes need widespread replication with appropriate modifications respecting local culture and practices in developing countries. Governments and national public health bodies need committed and persistent lobbying to persuade them to implement evidence-based comprehensive immunisation programmes for rubella through non-governmental organisations (NGO), ophthalmologists, professions allied to ophthalmology and paediatricians.

The surgical management and rehabilitation of children with cataract is far more complex than with adults and needs specialist surgeons with specialist equipment and precise calculation for aphakia correction which is still highly challenging in the high income nations. The use of contact lenses for optical rehabilitation is likely to fail. Aphakic spectacles remain the mainstay although an increasing use of intraocular lenses is now being seen, even in the very young infant. However, reoperation rates remain higher in these infants. Long-term follow-up is also vital, unlike in adults with 15-20% children developing secondary glaucoma.

ROP is becoming an increasing problem as health systems across the globe (particularly middle income nations and Asian cities) are achieving better survival rates of premature babies but do not have an equivalent ROP screening and

management structure in place. Cerebral visual impairment, the commonest cause of visual impairment in the developed nations is apparently less common in developing countries though this may be a reflection of poor survival rate and underreporting.

The lack of adequately trained paediatric anaesthetists adds to the problem. Early surgery in blinding eye conditions requires expert anaesthetic care and post-operative care. These are severely lacking in the countries that need to tackle childhood blindness with eye surgery at an early age.<sup>11,12</sup> As we contribute to developing paediatric eye care expertise in developing countries, we should aim for comprehensive paediatric eye care programmes which should include a team approach with paediatric anaesthetists and other professions (orthoptists, optometrists and nurses) who help us deliver eye care for children in our own environment.

In 1999 a review of the blindness control plan led to the formation of Vision2020 ([www.v2020.org](http://www.v2020.org)) a global initiative to tackle blindness, and placed childhood blindness for the first time as a WHO priority. This change seen within the context of the ambitious Millennium Development Goals ([www.un.org/millenniumgoals](http://www.un.org/millenniumgoals)) represents a significant hope for the future of blind children.

**Vision 2020** priorities for control of CB are corneal scarring in very poor countries, ROP in the rich, middle income and urban communities, and cataract, refractive error, glaucoma and low vision all over the world. The targets set have been to reduce global prevalence from 0.75/1000 to 0.4/1000. The priorities are:

1. To eliminate corneal scarring
2. To provide quality and prompt surgery for childhood cataract
3. Programmes for school screening of vision to detect and treat refractive errors.

While these public health issues need to be addressed, there is a present and immediate need for ophthalmic personnel with appropriate training to share their expertise within well designed programmes in comprehensive paediatric eye care to train and equip their colleagues in developing countries. As an ophthalmologist, I found it best to have a staged approach with an attempt to commit for the long-term (three to five years). A partnership approach with the beneficiaries

(hospital staff, community personnel, local NGO's and patient groups) and initial conversations to determine the present status and their needs, based on their experience and previous surveys of CB in the area is the first step. The next step would be to build up capacity in terms of training personnel. Without trained orthoptists / optometrists; theatre nurses, paediatric anaesthetists even the most brilliant surgery in children is unlikely to produce the desired visual benefit in CB. Equipment needs should be determined and the costing should include provision maintenance and training of biomedical engineers. Expertise should be built up in stages. Going back to the beneficiary centre every year for one or two weeks, offering email contact and providing support with tele-lectures (if available), even as part of your normal teaching sessions, are just some of the ways to keep up the momentum. If you are the leader of the team, be realistic in what can be achieved and delivered. Do less but do it well (remember, drops make oceans etc and remind yourself you are not here to eliminate CB in one go, but rather, just making a small contribution). Over ambitious projects which result in inadequate delivery of objectives is very bad for expectations and leaves everyone frustrated and gives volunteer work a bad name. Anticipate some of the challenges.

*Language, weather, crowding, safety and local culture are just some of the things to include in your briefings and plans.*

Over the past 15 years, I (Arvind Chandna) have had the privilege of being provided with opportunities to contribute to teaching, training, and capacity building of comprehensive paediatric eye care facilities leading to self-sustainability. Working in partnership with my colleagues in developing countries (doctors, orthoptists, optometrists, nurses, public health workers and paediatric anaesthetists) I have learnt more than I have ever taught. The continuing link through web based communication has formed lasting professional relationships and in many cases personal friendships.

At the Children's Eye Department, Alder Hey Hospital we have participated by providing training in all aspects of paediatric eye care at tertiary, secondary and primary level in partnership with international and local NGO's in the countries where the need is the greatest. We have provided

an environment for training of personnel in clinical ophthalmology and systems of care in our department to observers who have returned to make significant contributions to paediatric ophthalmology. As an active volunteer and Trustee I have provided guidance and review of long-term (three to five years) projects on developing paediatric eye centres at different levels in urban and rural areas. As a team (ophthalmologist, orthoptist and optometrist) we have contributed on an annual basis to a four year B.Sc. Vision Science Course which is helping train a combined cadre of orthoptist and optometrist to form a chain of personnel from the remote village to the tertiary centre. The first batch of enthusiastic graduates will start in January 2009. We are at the threshold of starting a long-term association with an international NGO in providing training to ophthalmologists, orthoptist / optometrists and theatre nurses on a rolling six-month fellowship programme over the next five years. Each of these numerous experiences over the last 15 years has been unique. It has provided us with challenges, an education for ourselves, rewards in seeing achievements which we thought were not possible and an abiding respect for our overseas colleagues working against considerable odds with motivation and dedication. This has not been easy. With the help of a motivated team in the department, encouragement and support from medical directors and senior management at the hospital it has been made possible.

As ophthalmologists we can all contribute to this effort. The essential basic ingredients are: awareness on our part of the significance of the problem, a will to transfer our skills and expertise to those less fortunate in training, and a team approach with support from hospital management. Link programmes exist and are run by International Centre for Eye Health, UK (<http://www.iceh.org.uk/>). Importantly, ensuring that the programme is aimed towards the common causes of treatable / avoidable blindness, a partnership approach is adopted; the aim is to build capacity by including infrastructure development in addition to training of teams of personnel. Above all, you must convince yourself that within the lifetime of the project you will be able to transfer the skills necessary and that the programme will be sustainable (for expertise and finance) for long after your contribution has ceased and you have moved on to the next step. We are in the exciting position of being able to make a difference within our career span that will impact future generations for decades to come. Are you willing to be part of the change? **EN**



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#### Take Home Message

- Childhood blindness is of greater significance than originally thought.
- Much of childhood blindness is treatable and preventable.
- You have a significant role to play in the UK to impact global blindness.