

Childhood blindness in the context of VISION 2020 — The Right to Sight

Clare Gilbert¹ & Allen Foster²

The major causes of blindness in children vary widely from region to region, being largely determined by socioeconomic development, and the availability of primary health care and eye care services. In high-income countries, lesions of the optic nerve and higher visual pathways predominate as the cause of blindness, while corneal scarring from measles, vitamin A deficiency, the use of harmful traditional eye remedies, and ophthalmia neonatorum are the major causes in low-income countries. Retinopathy of prematurity is an important cause in middle-income countries. Other significant causes in all countries are cataract, congenital abnormalities, and hereditary retinal dystrophies. It is estimated that, in almost half of the children who are blind today, the underlying cause could have been prevented, or the eye condition treated to preserve vision or restore sight.

The control of blindness in children is a priority within the World Health Organization's VISION 2020 programme. Strategies need to be region specific, based on activities to prevent blindness in the community — through measles immunization, health education, and control of vitamin A deficiency — and the provision of tertiary-level eye care facilities for conditions that require specialist management.

Keywords: Blindness/prevention and control; Blindness/etiology; Child; Socioeconomic factors; Program development (*source: MeSH*).

Mots clés: Cécité/prévention et contrôle; Cécité/étiologie; Enfant; Facteur socioéconomique; Développement programme (*source: INSERM*).

Palabras clave: Ceguera/prevenición y control; Ceguera/etiología; Niño; Factores socioeconómicos; Desarrollo de programa (*fuelle: BIREME*).

Bulletin of the World Health Organization, 2001, **79**: 227–232.

Voir page 231 le résumé en français. En la página 232 figura un resumen en español.

Introduction

The control of blindness in children is considered a high priority within the World Health Organization's (WHO's) VISION 2020 — The Right to Sight programme (1). There are several reasons for this. Firstly, children who are born blind or who become blind and survive have a lifetime of blindness ahead of them, with all the associated emotional, social and economic costs to the child, the family, and society. Indeed, the number of "blind years" due to all causes of blindness in children is almost equal to the number of "blind years" due to cataract in adults. Secondly, many of the causes of blindness in children are either preventable or treatable. Thirdly, many of the conditions associated with blindness in children are

also causes of child mortality (e.g. premature birth, measles, congenital rubella syndrome, vitamin A deficiency, and meningitis). Control of blindness in children is, therefore, closely linked to child survival.

Reducing visual loss in children poses particular challenges which are different from the challenges of controlling adult blindness. Children are born with an immature visual system and, for normal visual development to occur, they need clear, focused images to be transmitted to the higher visual centres. Failure of normal visual maturation (amblyopia) cannot be corrected in adult life, so there is a level of urgency about treating childhood eye disease which does not necessarily apply to adult conditions. The assessment of vision and examination of the eyes also pose particular difficulties, which require time and experience on the part of the examiner. Furthermore, children's eyes cannot be considered as smaller versions of adult eyes, because they respond differently to medical and surgical treatment.

Definitions

UNICEF defines a *child* as an individual aged less than 16 years. WHO defines *blindness* as a corrected visual acuity in the better eye of less than 3/60, and *severe*

¹ Senior Research Fellow, Department of Epidemiology and International Eye Health, Institute of Ophthalmology, Bath Street, London EC1V 9EL, England (email: clare.gilbert@ucl.ac.uk). Also Medical Adviser to Sight Savers International. Correspondence should be addressed to this author.

² Senior Lecturer in International Eye Health, London School of Hygiene and Tropical Medicine, London, England. Also Medical Adviser to Christoffel-Blindenmission (Christian Blind Mission) International.

visual impairment as a corrected acuity in the better eye of less than 6/60.

Blindness in children

Prevalence and magnitude

As blindness in children is relatively rare, accurate prevalence data are difficult to obtain, because very large samples are required for population-based prevalence surveys. Some data are, however, available from population surveys that included children, from community-based rehabilitation programmes, and from registers of the blind. These sources suggest that the prevalence of blindness in children varies according to socioeconomic development and under-5 mortality rates. In low-income countries with high under-5 mortality rates, the prevalence may be as high as 1.5 per 1000 children, while in high-income countries with low under-5 mortality rates, the prevalence is around 0.3 per 1000 children (2). If this correlation is used to estimate the prevalence of blindness in children, the number of blind children in the world is estimated to be 1.4 million (3). Approximately three-quarters of the world's blind children live in the poorest regions of Africa and Asia, where the prevalence is high, and the child population large.

Incidence

The incidence of blindness in children is very difficult to ascertain, requiring either very large longitudinal

studies, accurate registers of the blind, or reliable active surveillance systems. Data from industrialized countries suggest that the incidence of blindness in children resulting from acquired conditions has declined over the last few decades, but there are no reliable data from developing countries. In the latter, a high proportion of children who become blind die within a few years of becoming blind, either from systemic complications of the condition causing blindness (e.g. vitamin A deficiency, measles, meningitis, and congenital rubella syndrome), or because poor parents have more difficulty in caring for their blind children than their sighted siblings. Estimates of the number of prevalent cases of blindness in children therefore markedly underestimate the magnitude of the problem of blindness in children.

Determining the causes of blindness in children

Methodology. Over the last few years much of the information on the causes of blindness in children has been collected using a methodology developed by the International Centre for Eye Health, London, England, in collaboration with WHO. This uses standard definitions and a reporting form, which allow comparison of the collected data (4); and the causes are classified according to the main anatomical site of the abnormality (Table 1), as well as the underlying etiology (Table 2) (5, 6). The main advantage of having two classification systems is that data on the anatomical site can be collected for all children, while etiological data, although more

Table 1. Causes of severe visual impairment and blindness in children, by anatomical site of the abnormality, by etiological category, and by World Bank region^{a,b}

Abnormality or etiology	Causes of severe visual impairment and blindness								
	High ← Socioeconomic status → Low								
	EME	FSE	LAC	MEC	China	India	OAI	SSA	All
Site of abnormality (%)									
Retina	25	44	47	38	25	22	21	24	29
Cornea	1	2	8	8	4	28	21	31	15
Whole globe	10	12	12	15	26	24	21	9	16
Lens	8	11	7	20	19	11	19	9	12
Optic nerve	25	15	12	7	14	6	7	10	12
Glaucoma	1	3	8	5	9	3	6	7	5
Uvea	2	5	2	4	1	5	3	4	3
Other (e.g. CNS ^c)	28	8	4	3	2	1	2	6	8
Etiological category (%)									
Hereditary	45	18	22	54	31	26	27	24	31
Intrauterine	7	6	8	2	0	1	3	3	4
Perinatal	24	28	28	1	2	2	9	7	12
Childhood	10	5	10	6	14	29	14	31	17
Unknown	14	43	32	37	53	42	47	35	36
No. of countries included	7	4	8	3	1	1	6	10	40
No. of children examined	1683	504	1007	821	1131	1890	850	1407	9293

^a World Bank regions: EME = Established Market Economies; FSE = Former Socialist Economies; LAC = Latin America and Caribbean; MEC = Middle East Crescent; China; India; OAI = Other Asia and Islands; SSA = Sub-Saharan Africa.

^b Source: Childhood Blindness Database, International Centre for Eye Health, London, England.

^c CNS = central nervous system.

difficult to obtain, are more useful for planning relevant intervention programmes.

Limitations and potential bias. Most of the available data on the causes of blindness in children from developing countries have been obtained from examining children in schools for the blind, since the number of blind children identified in community surveys is generally very small. For example, in a population-based survey of blindness in India which included 4050 children aged 6–15 years, only two were blind and five were severely visually impaired (R. Thulasiraj, personal communication, 2000). While studies of schools for the blind allow a large number of children to be examined over a short period of time by one observer using standard methods, the data are potentially biased. It is thought that in most developing countries only 10% of blind children are in special schools; if the causes of blindness are different in children that receive special education compared with those that do not, the data will be biased. Schools for the blind rarely admit children of preschool age or those with multiple disabilities. Blind children from poor, remote rural areas are also likely to be under-represented. Three studies — in India (7), Mongolia (C. Gilbert, unpublished data) and Uganda (8) — allowed the comparison of the causes of blindness in blind children identified in the community, with children from the same geographical region who were at schools for the blind. The causes were broadly similar, except for optic atrophy and central nervous system disorders, which tended to be under-represented in children receiving special education. A further limitation of the method is that most children in schools for the blind were born 8 to 15 years ago, so the data cannot reflect the impact of recent interventions, such as greatly improved coverage of measles immunization.

Findings. Given the above limitations, the available data demonstrate that there is wide regional variation in the causes of blindness in children (Table 1 and Table 2), and in the cause-specific prevalence of blindness (Fig. 1). In the poorest countries of the world, corneal scarring due to vitamin A deficiency, measles infection, ophthalmia neonatorum, and the effects of harmful traditional eye remedies predominate. For example, in a study of children in schools for the blind in India, where 1318 children in nine states were examined, 26.4% of blindness was due to corneal scarring (principally attributed to vitamin A deficiency), 20.7% to congenital anomalies, 19.3% to retinal dystrophies, 12.3% to cataract, uncorrected aphakia, and amblyopia, and only 5.9% to optic atrophy. However, at the other end of the socioeconomic spectrum, a study of children in schools for the blind in the United States of America revealed that 19% of 2553 children were cortically blind, and 12% had visual loss from optic atrophy or optic nerve hypoplasia (9).

In all regions of the world, cataract, retinal diseases (mainly hereditary retinal dystrophies), and congenital abnormalities affecting the whole eye are

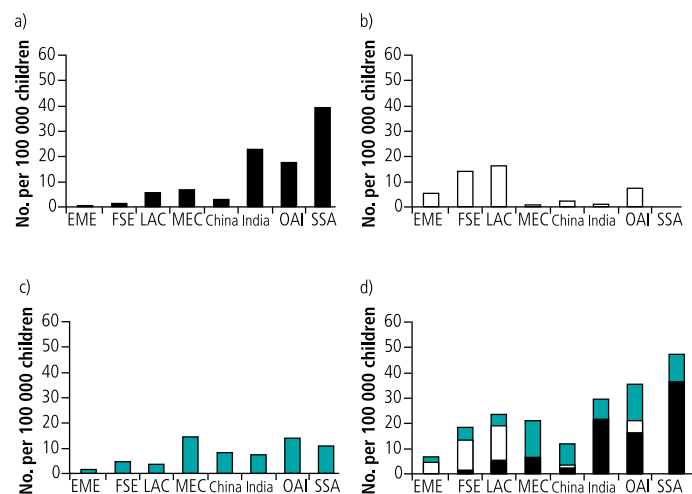
Table 2. Summary of estimates of the number of children worldwide with severe visual impairment and blindness, by anatomical site of the abnormality and etiological category^a

Site of abnormality		Etiological category	
Retina	380 000	Unknown	560 000
Cornea	260 000	Hereditary diseases	420 000
Whole globe	250 000	Childhood factors	280 000
Lens	190 000	Perinatal factors	100 000
Optic nerve	140 000	Intrauterine factors	40 000
Glaucoma	90 000		
Other (e.g. CNS ^b)	50 000		
Uvea	40 000		
Total	1 400 000	Total	1 400 000

^a Source: ref. 3.

^b CNS = central nervous system.

Fig. 1. Estimates of the cause-specific prevalence of severe visual impairment and blindness in children (number per 100 000 children) due to avoidable causes: a) corneal scarring; b) retinopathy of prematurity; c) cataract; d) corneal scarring, retinopathy of prematurity, and cataract; by World Bank region^{a,b}



^a See footnote a, Table 1.

^b See footnote b, Table 1.

WHO 01.22

important causes of blindness. The patterns of disease by underlying etiology also suggest that genetic diseases are important worldwide. Perinatal conditions (particularly retinopathy of prematurity (ROP)) and lesions of the central nervous system) are more important in high-income countries, while acquired conditions in childhood are more important in low-income countries. In middle-income countries the picture is mixed, but ROP is emerging as an important, potentially avoidable cause of blindness (10).

Avoidable causes

The term *avoidable* encompasses preventable and treatable causes. Conditions amenable to primary prevention (i.e. where the condition causing blindness could have been entirely prevented) include measles infection, vitamin A deficiency, ophthalmia

neonatorum, the use of harmful traditional eye medication remedies, and congenital rubella syndrome. Conditions that could have been treated early to prevent blindness (i.e. secondary prevention) include glaucoma and ROP. Causes of blindness where sight can be restored (i.e. tertiary prevention) include cataract and selected cases of corneal scarring. The provision of magnifiers and other low-vision devices is also important in restoring useful visual function. The main avoidable causes of blindness in children are shown in Table 3, together with estimates of the number of prevalent cases affected.

The available data suggest that, worldwide, corneal scarring is the single most important cause of avoidable blindness, followed by cataract and ROP. Control of these conditions is given priority in WHO's VISION 2020 programme, together with correction of significant refractive errors and provision of services for low vision.

Control of blindness in children

Good primary health care and personnel trained in primary eye care are essential for the control of blindness in children. This applies particularly to developing countries, where a high proportion of blindness in children is due to preventable conditions acquired during childhood. Many of the causes of corneal scarring in children would be prevented if the following eight essential elements of primary health care were in place: services for immunization; maternal and child health care; health education; good nutrition; essential drugs; clean water supplies and good sanitation; control of endemic diseases; and treatment of common conditions. In many countries, measles immunization programmes are reaching target coverage levels, and the number of measles cases has been dramatically reduced. There is anecdotal evidence that the success of the Expanded Programme on Immunization (EPI) is also reducing corneal ulceration and scarring in children (11). International efforts to control vitamin A deficiency in children, stimulated by evidence that vitamin A

deficiency in childhood is associated with an increased mortality rate (12), are also likely to have an impact, thus reducing corneal scarring in childhood. Approaches to reduce vitamin A deficiency include the promotion of home gardening; health and nutrition education; fortification of commonly consumed foods; food supplementation programmes; and supplementation for at-risk populations with high-dose vitamin A in capsule or syrup form. Linking vitamin A supplementation to routine immunization programmes and by distributing vitamin A supplements on immunization days is a recommended strategy to increase coverage (13), and this policy is being adopted by many countries.

Primary eye care includes promotion of eye health, action in the community to prevent conditions which cause blindness, and recognition and treatment of common eye diseases by trained community-level health workers. Primary eye care also includes the identification of children who need referral for ophthalmological assessment and treatment — such as any blind child or a child with a white pupil or corneal ulcer. Different cadres of primary health care worker have different roles: traditional birth attendants, for example, can prevent ophthalmia neonatorum and examine the eyes of the newborn for structural abnormalities.

At the secondary level of care, an eye surgeon should be able to carry out a full examination and assessment, make a provisional diagnosis, manage corneal ulcers in children, and prescribe simple low-vision devices for children with less complex problems. School vision-testing programmes to identify children with significant refractive errors should also be organized and supported from the secondary level. For effective referral, good communication needs to be established between staff working in the primary and tertiary levels.

The management of conditions requiring surgical intervention is more complex in children than in adults, and requires a team of well-trained and well-equipped personnel. Ideally, ophthalmologists providing services for children at tertiary centres need a child-centred approach, and they should also

Table 3. Estimates of the number of prevalent cases of children with severe visual impairment and blindness due to avoidable causes, by level of socioeconomic development

High-income countries (EME and FSE) ^{a, b}		Middle-income countries (LAC, MEC and China) ^{a, b}		Low-income countries (India, OAI and SSA) ^{a, b}	
ROP ^c	9000	Cataract	45 000	Corneal scar	200 000
Teratogens	5400	ROP	29 000	Cataract	133 000
Cataract	5400	Glaucoma	17 000	Glaucoma	60 000
Glaucoma	2000	Teratogens	12 000	Optic atrophy	60 000
Total	21 800	Total	103 000	Total	453 000

^a See footnote a, Table 1.

^b Source: ref. 3.

^c ROP = retinopathy of prematurity.

be trained in the required specialized surgical techniques and in postoperative management. Effective communication with parents to ensure their involvement is also essential. An anaesthetist will be required for young children, and trained nurses, refractionists, and paramedics are all essential members of the team. Tertiary centres should be able to provide surgical services of high quality for the management of cataract, glaucoma, and corneal scarring. Screening for ROP in preterm infants, as well as the organization and provision of low-vision services, is also a tertiary-level function. Tertiary centres should take responsibility for research; the training of trainers for primary- and secondary-level programmes; and for supporting, supervising, motivating, and providing feedback to staff in secondary-level centres.

VISION 2020 targets

The following targets for the control of blindness in children (Box 1), in accordance with the three components of the VISION 2020 programme — measures for disease control, human resources development, and appropriate technology and infrastructure development — were approved at a recent scientific meeting (3).

In addition to the public health measures outlined in Box 1, many strategies for the control of blindness in children are already being implemented, e.g. vision screening in schools in India, screening for ROP in Latin American countries and India, training in paediatric eye care in India. The challenge is to ensure that the control of blindness in children is an explicit aim of all national prevention of blindness programmes, and that appropriate activities are planned and implemented in an integrated fashion. ■

Box 1. VISION 2020 targets for the control of blindness in children

Specific disease-control measures

- Reduce the global prevalence of childhood blindness from 0.75 per 1000 children to 0.4 per 1000 children by the year 2020.
- Eliminate corneal scarring caused by vitamin A deficiency, measles, or ophthalmia neonatorum.
- Eliminate new cases of congenital rubella syndrome.
- Provide appropriate surgery to all children with congenital cataract, with immediate and effective optical correction, in suitably equipped specialist centres.
- Ensure that all babies at risk of ROP have a fundus examination by a trained observer 6–7 weeks after birth. Cryo or laser treatment should be provided for all those with threshold disease.
- See that all schoolchildren have a simple vision-screening examination, and that glasses are provided to all who have a significant refractive error. This service should be integrated into the school health programme.

Human resources development

- Ensure that prevention of childhood blindness is an explicit aim of all primary health care programmes.
- Ensure that all secondary-level eye clinics have facilities to provide appropriate glasses for children with significant refractive errors.
- Provide training so that there will be one refractionist per 100 000 people by the year 2010.
- Provide training so that there will be at least one worker to manage low vision for every 20 million people by 2010, and for every 5 million by 2020.
- Ensure that one ophthalmologist is trained in the management of paediatric eye conditions for every 50 million people by 2010, and one per 10 million people by 2020.

Appropriate technology and infrastructure development

- Ensure the development of low-cost, high-quality, low-vision devices, which should be widely available, even in low-income countries.
- Establish a network of specialist “child eye care” tertiary centres.

Résumé

Cécité de l'enfant dans le contexte de VISION 2020 – Le droit à la vue

Les principales causes de cécité chez l'enfant sont très différentes d'une région à l'autre et sont largement déterminées par le niveau de développement socio-économique et par la possibilité d'accès aux soins de santé primaires et aux services de soins oculaires. Dans les pays à haut revenu, les causes de cécité prédominantes sont les lésions du nerf optique et des voies optiques supérieures, tandis que dans les pays à faible revenu les causes majeures sont les cicatrices cornéennes dues à la rougeole, l'avitaminose A, l'utilisation de remèdes traditionnels dangereux et la conjonctivite gonococcique du nouveau-né. La rétinopathie des prématurés est une cause importante dans les pays de revenu intermédiaire. Parmi les autres causes importantes dans tous les pays figurent la cataracte, les anomalies

congénitales et les dystrophies rétiniennes héréditaires. On estime que chez près de la moitié des enfants qui sont aujourd'hui aveugles, la cause sous-jacente aurait pu être évitée, ou l'affection oculaire traitée pour préserver ou restaurer la vision.

La lutte contre la cécité de l'enfant est l'une des priorités du programme VISION 2020 de l'Organisation mondiale de la Santé. Les stratégies doivent être adaptées aux régions, reposer sur des activités de prévention de la cécité dans la communauté – vaccination antirougeoleuse, éducation sanitaire et lutte contre la carence en vitamine A – et sur l'existence d'établissements de soins oculaires de niveau tertiaire pour les affections qui exigent une prise en charge par un spécialiste.

Resumen

La ceguera infantil en el contexto de VISIÓN 2020: el derecho a ver

Las causas principales de ceguera en la infancia varían ampliamente de una región a otra, y están determinadas en gran parte por el desarrollo socioeconómico y por la disponibilidad de servicios de atención primaria y oftalmológica. En los países de ingresos altos las causas de ceguera predominantes son las lesiones del nervio óptico y de las vías ópticas superiores, mientras que en los países de bajos ingresos las causas principales son la cicatrización corneal por sarampión, el déficit de vitamina A, el uso de remedios oculares tradicionales nocivos y la oftalmía del recién nacido. La retinopatía del prematuro es una causa importante en los países de ingresos medios. Otras causas relevantes en todos los países son la catarata, las anomalías congénitas y las distrofias retinianas hereditarias. Se estima que, en casi

la mitad de los niños que hoy están ciegos, o bien podría haberse prevenido la causa fundamental, o bien se podría haber tratado la afección ocular para conservar o restablecer la vista.

La lucha contra la ceguera infantil es una prioridad dentro del programa VISIÓN 2020 de la Organización Mundial de la Salud. Es necesario que las estrategias sean específicas para cada región, y que estén basadas en actividades de prevención de la ceguera en la comunidad —mediante iniciativas de inmunización antisarampionosa, educación sanitaria y lucha contra el déficit de vitamina A— y en el suministro de servicios de atención oftalmológica de nivel terciario para las afecciones que requieren la intervención de especialistas.

References

1. *Global initiative for the elimination of avoidable blindness*. Geneva, World Health Organization, 1998 (unpublished document WHO/PBL/97.61).
2. **Gilbert CE et al.** Prevalence of blindness and visual impairment in children — a review of available data. *Ophthalmic Epidemiology*, 1999, **6**: 73–81.
3. *Preventing blindness in children: report of a WHO/IAPB scientific meeting*. Geneva, World Health Organization, 2000 (unpublished document WHO/PBL/00.77).
4. **Gilbert C et al.** Childhood blindness: a new form for recording causes of visual loss in children. *Bulletin of the World Health Organization*, 1993, **71**: 485–489.
5. **Hornby SJ et al.** The causes of childhood blindness in the People's Republic of China: results from 1131 blind school students in 18 Provinces. *British Journal of Ophthalmology*, 1999, **83**: 929–932.
6. **Rahi J et al.** Childhood blindness in India: causes in 1318 blind school students in 9 states. *Eye*, 1995, **9**: 545–550.
7. **Sil AK.** *Childhood blindness in West Bengal* [Dissertation]. London, University of London, 1998.
8. **Waddell KM.** Childhood blindness and low vision in Uganda. *Eye*, 1998, **12**: 184–192.
9. **Steinkuller PG et al.** Childhood blindness. *Journal of Aapos*, 1999, **3**: 26–32.
10. **Gilbert C et al.** Retinopathy of prematurity in middle-income countries. *Lancet*, 1997, **350**: 12–14.
11. **Foster A, Yorston D.** Corneal ulceration in Tanzanian children: relationship between measles and vitamin A deficiency. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 1992, **86**: 454–455.
12. **Sommer A, West KP, eds.** *Vitamin A deficiency. Health, survival and vision*. Oxford, Oxford University Press, 1996.
13. *Integration of vitamin A supplementation with immunization: policy and programme implications. Report of a meeting, 12–13 January 1998, UNICEF, New York*. Geneva, World Health Organization, 1998 (WHO/EPI/GEN/98.07).