# OCULAR FINDINGS AMONG CHILDREN IN SAMBURU HANDICAP AND REHABILITATION PROGRAMME

A dissertation submitted in part fulfilment for the degree of Masters of Medicine (Ophthalmology)

University of Nairobi

By

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## **DECLARATION**

This dissertation is my original work and has not been presented for a degree at any other university

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## **DEDICATION**

To the women in my life; my dear mum, my loving wife and my two beautiful daughters.

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## LIST OF ABBREVIATIONS

BCVA -Best corrected visual acuity

CRS - Congenital Rubella syndrome

ICEH -International centre for eye health

LVS -Low vision services

OCO - Ophthalmic clinical officer

OR -Objective refraction

PCIOL - Posterior chamber intraocular lens

PHC - Primary health care

PBL -Programme for prevention of blindness

RBL -Retinoblastoma

SHERP - Samburu handicap education and rehabilitation programme

SR - Subjective refraction

SVI -Severe visual impairment

V.A - Visual acuity

VAD - Vitamin a deficiency

VI - Visual impairment

WHO - World health organization

#### **SUMMARY**

#### Background:

Samburu handicap education and rehabilitation programme (SHERP) is a community based organisation which caters for children with various handicaps from all over Samburu district. Its main aim is to provide a home for these children, rehabilitate them and integrate them back into normal schools.

#### Aims/Objectives:

To determine the prevalence and pattern of eye diseases, and their association with other handicaps in children under SHERP.

#### Methodology:

A cross sectional community based study in which 272 children registered under SHERP were examined.

#### Results:

272 children out of a total of 341 were examined. Majority of the children were male (59.2%). The youngest child was aged 4 years while the oldest was 15 years. The mean age was 11 years with 34% of the children being in the 13-15 year age bracket. Amongst the children, 27% had ocular anomalies, 21% had mental retardation, 18% were deaf and 21.3% had various limb anomalies including paralytic disorders. Refractive errors were the commonest ocular anomaly (40.8%) while corneal scars and cataracts were seen in 17% and 5.2% of children respectively. 30% of mentally retarded children had ocular anomalies with refractive errors and optic nerve atrophy having a prevalence of 7.8% and 6.2% respectively. Both findings were statistically significant. Cataracts and corneal scars were each seen in 6.2%.Both were not statistically significant.35% of deaf children had ocular anomalies, most being refractive errors (26%) and cataracts (7.3%). These results were both were statistically significant. The only finding in children with paralytic diseases was refractive errors (29.7%). This was not statistically significant. 70% of the children had normal visual acuity (6/6-6/18), while 21% had visual impairment.

Only 0.73% had severe visual impairment and 5.9% were blind. The major causes of visual impairment were refractive errors (52.6%) and corneal scars (21%). The major causes of severe visual impairment/ blindness were corneal opacities (44.4%) and optic nerve disease (33.3%).

#### Conclusions

There was a high prevalence of ocular anomalies (27%) in children under SHERP. Refractive errors were the commonest eye condition causing visual impairment while the commonest cause of severe visual impairment and blindness was corneal scars.

#### Recommendations

Screening for ophthalmic problems in deaf and mentally retarded children should be done as soon as the conditions are diagnosed to enable early intervention. There is need for proper record keeping in SHERP. This should include complete demographic details, medical and family social history of the children. Low cost, durable spectacles should be supplied to these children. Studies should be done in both schools for the deaf and mentally getarded involving larger sample sizes to shed more light on ocular disorders in these children.

## 1.0 INTRODUCTION AND LITERATURE REVIEW

Visual input accounts for a major part of the sensory stimuli that are essential for the complete development of a child in its early years. Visual deprivation in the early years has far reaching psychological, educational and economic effects to the child; family and society.

The cost of lost productivity, rehabilitation and education of the blind constitutes a significant economic burden, particularly in developing countries. Since blindness directly impacts on economic activity and quality of life, the prevention and cure of blindness can provide enormous savings and facilitate society development. Most of the eye diseases which cause blindness can either be prevented or cured <sup>2</sup>.

There are approximately 1.5 million blind children in the world with up to 0.5 million new cases /year <sup>2</sup>. The causes of severe visual impairment (SVI) and blindness vary worldwide, with nutritional and infections being more common in developing countries (mainly Asia and Africa) compared to hereditary and developmental disease in the developed world (America and Europe) <sup>3</sup>.

Early recognition, treatment and prevention of avoidable causes of SVI and childhood blindness have been shown to yield good results <sup>2</sup>. To make an impact on the incidence of low vision and childhood blindness, it is important to find out what their major causes are in our country.

Various studies have estimated that there is a high prevalence (9-11/10000) of childhood blindness in Africa <sup>4, 5</sup>. Njuguna in 2000 found that in Kenyan schools for the blind, 64.8% of childhood blindness was avoidable <sup>6</sup>. The 1999 census showed that 1% of Kenyans have physical disabilities and 24% of these are visually handicapped <sup>7</sup>. Thus, 0.2% of Kenya's population is visually handicapped.

Blindness in children poses a major health problem in terms of lifetime economic and social deprivation, economic and social burden to the government and society.

This can be viewed in terms of blind years. (Number of blind individuals × average number of years a person lives with blindness). In terms of priority, blind years is more important than the absolute numbers of blind children. Some authorities have argued that restoring the sight of one cataract blind child is equivalent to restoring sight of 10 elderly adults from cataract <sup>8</sup>.

Handicap occurs in various forms, for example, limb anomalies, visual impairment, deafness and mental retardation. Handicap could be due to congenital defects or acquired causes.

Congenital causes occur due to intrauterine insult by teratogens or chromosomal anomalies. Various studies have shown an increased incidence of ocular anomalies in various physical handicaps and in mentally retarded subjects <sup>9, 10, 11</sup>. Acquired causes of visual handicap are either preventable or treatable, thus avoidable.

Visually impaired or blind children should be taught daily living skills early, as it is difficult to motivate older children. Skills to be imparted early include aspects such as personal grooming and hygiene <sup>5</sup>.

Visually handicapped children have been noted to have slower social development and require a multidisciplinary approach comprising special education teachers and health professionals to enable them integrate in society <sup>12</sup>. The children may need to attend special schools to learn Braille and also orientation and mobility skills <sup>13</sup>. Visually handicapped children can also be integrated into normal schools. Examination techniques have been modified and students allocated more time. This has been achieved through interaction between examination officers in charge of various test subjects and experts in special education <sup>14</sup>.

# 1.1.0 CONGENITAL CAUSES OF OCULAR AND PHYSICAL ANOMALIES

Congenital causes are due to teratogens or chromosomal anomalies Most teratogens are drugs, environmental chemicals, infectious agents such as rubella, radiation or deficiency states.

Congenital rubella results from transplacental transmission of virus to the fetus from an infected mother, usually during the first trimester. Ocular complications include retinopathy, nuclear cataracts, microphthalmos, glaucoma and other miscellaneous complications like stromal keratopathy, iris atrophy, and extreme refractive errors. Rubella cataracts are usually bilateral and occur in 50% of cases. Viruses have been cultured from the lens long after birth <sup>19</sup>. Khandekar studied 32 patients with congenital rubella syndrome (CRS). Cataracts, retinitis, microphthalmos and glaucoma occurred in 11, 16, 6, 4 patients respectively. The children who underwent surgery had significantly poorer long term visual outcome than those not operated <sup>20</sup>.

#### 1.1.1 Down's syndrome

This occurs due to a chromosomal anomaly (Trisomy 21). It is the commonest of the trisomy syndromes and is the result of aneuploidy involving the smallest human chromosome. Incidence increases with maternal age; at 30 years it occurs in 1:1000 births. By 40 years it occurs in 9: 1000 births. 75% of these embryos are aborted spontaneously <sup>21</sup>.

Children with Down's syndrome exhibit epicanthic folds, oblique palpebral features, a protruding tongue, flat nasal bridge, and low malformed ears. Nystagmus and strabismus are common with esotropia occurring in 90% and exotropia in 10% <sup>22</sup>. Refractive errors occurred in 52.7% and strabismus in 21.8% of children with Down's syndrome <sup>23</sup>. Kim J et al examined 123 children with Down's syndrome and found high rates of exotropia but noted no Brushfield spot <sup>24</sup>.

Bodenmueller et al showed that children with Down's syndrome and keratoconus undergoing penetrating keratoplasty have a worse outcome than other keratoconus patients. This is probably due to a high rate of emergency procedures, presence of lid anomalies and very advanced keratoconus requiring bigger graft sizes. Deep lamellar keratoplasty is recommended as it is not an intraocular procedure and also avoids endothelial rejection <sup>25</sup>.

#### 1.2.0 HANDICAPS WITH OCULAR ASSOCIATIONS

#### 1.2.1 Deafness

Deaf children are heavily reliant on the sense of vision in order to develop efficient communication skills and explore the world around them.

Any ophthalmic disorder may thus negatively impact on this process, especially if it is unrecognized in the early years of life. These disorders may be correctable (such as myopia) or treatable (such as cataract), and their early identification is of the utmost importance to optimize language development (spoken or sign, or both) and develop social cognition. Those children with non-correctable and non-treatable visual disorders, like retinitis pigmentosa in Usher syndrome, require multiple environmental adaptations and appropriate support services and information <sup>10</sup>.

Hanioglu et al examined 104 deaf children and found that 40.4% had ophthalmological abnormalities (91% of which were refractive and 9% had posterior segment disease) <sup>26</sup> Leguire et al and Elango et al also showed that refractive errors occurred in 49% and 57.6% respectively of deaf children <sup>27, 28</sup>. In both studies, rubella retinopathy was common. Nicole A et al examined 78 deaf children and found that 33% ocular anomalies. Most were mild, for example, altered retinal pigmentation. She postulated that this was likely secondary to congenital rubella or genetic defects affecting pigmentation <sup>29</sup>.

#### 1.2.2 Mental retardation

Mental retardation is associated with an increased incidence of ocular anomalies<sup>30</sup>. Mwanza J et al in Zaire examined mentally retarded children and found that 15% had refractive errors and 16.4 % had optic atrophy <sup>31</sup>.

In a study to show the incidence of ophthalmic disorders in mentally handicapped, Bothe N et al found optic atrophy in 24%, cataracts in 17%, anterior segment malformations in 12% and refractive errors in 6% of patients <sup>11</sup>.

Cataracts in patients with mental and physical handicap should be managed by posterior chamber intra ocular lens implantation (PCIOL). Accurate IOL measurement by biometry and small incision surgery is imperative <sup>32</sup>.

#### 1.3.0 CLASSIFICATION OF CAUSE OF VISUAL LOSS

In 1991, WHO/PBL developed a standardized classification system for causes of visual loss in childhood. This was due to difficulties in comparing data from different studies <sup>33</sup>.

There are two ways of classifying the causes of visual loss. The first describes the part of the eye affected (anatomical):

- whole eye e.g. microphthalmos, anophthalmos
- cornea, e.g. corneal scarring, keratoconus
- lens, e.g. cataract, aphakia
- uvea, e.g. aniridia, uveitis
- retina e.g. Retinal dystrophies
- optic nerve e.g. optic atrophy, optic nerve hypoplasia.
- Eye appears normal e.g. cortical blindness, amblyopia.

The second (aetiological), depends on the time of onset of the condition leading to visual loss.

- conception e.g. genetic disease, chromosomal abnormalities.
- intrauterine e.g teratogens i.e rubella, toxoplasmosis, thalidomide.
- perinatal period e.g. retinopathy of prematurity, birth injury.
- Childhood e.g. vitamin A deficiency, measles, trauma.
- unknown/ cannot be determined e.g. developmental abnormalities.

The anatomical classification is especially useful where past medical records may be difficult to get. It may also be useful in describing the patterns of childhood blindness between different countries and in the same country over time.

Most of the causes of childhood visual loss are avoidable (preventable or treatable). Measles, congenital rubella, ophthalmia neonatorum are preventable while glaucoma, cataract and ROP stage 3 can be treated if diagnosed early.

#### 1.4.0 INTERVENTIONS

A variety of strategies have been developed against major causes of childhood blindness and resulting visual loss. Most of them are directed towards public health measures rather than eye care because of many complex factors contributing to visual loss.

- 1. Primary prevention: -prevention of occurrence of disease in a population. Good PHC is essential for prevention of childhood blindness. Implementation of the 8 essential elements of PHC would virtually eliminate corneal scarring
- 2. Secondary prevention: this is the prevention of sight threatening complication and visual loss once there is a disease outbreak. Secondary level services need to be developed to provide low vision, refractive services for children and prompt treatment of corneal ulcers.
- 3. Tertiary prevention: minimisation of the visual disability resulting from previous eye disease or injury. Tertiary level care needs a well equipped team of trained personnel competent in anaesthesia, surgery, optical and low vision care in children.
- 4. Quarternary prevention: this is the rehabilitation of the incurably blind.

In developing nations, primary and secondary prevention is crucial. This is because most of the causes of SVI/BL are preventable.<sup>6</sup> Tertiary prevention is difficult to achieve due to lack of finances, and hence resources.

Childhood vaccination is a crucial component of primary health care. Measles is the most common precipitant of vitamin A deficiency (VAD). A high titre, live attenuated vaccine which is safe, immunogenic and effective is available.

Meta analysis of 10 cohort studies and 2 case control studies showed a higher mortality rate in unimmunized children compared to immunized children <sup>36</sup>. The study showed that the lower mortality in the immunized is only partially explained by the protective effect against measles. The reasons for this are not known and further randomized clinical trials are warranted. Measles tends to be particularly serious in children with protein- energy malnutrition, with a high rate of complications and mortality. Barclay et al demonstrated a dramatic reduction of both with vitamin A supplementation <sup>37</sup>.

#### 1.4.1 COST OF INTERVENTION

The economic loss over 10 years due to childhood cataract is estimated to be between 1000-6000 US Dollars <sup>34</sup>. Estimates in India, assuming a blind child has an average of 33 years of blindness, and that 14% of childhood blindness is due to cataracts, calculate a lifetime loss of earning capacity of 3500 US Dollars. The cost of cataract intervention in India is approximately 100-200 US Dollars, depending on facilities <sup>35</sup>. In Kenya cataract surgery cost varies per hospital depending on subsidies from Non Governmental Organizations. Kenyatta National Hospital, the main referral centre charges approximately 100 US Dollars.

#### 1.4.2 BARRIERS TO COMBATING VISUAL HANDICAP

There is a dire shortage of human resources, who include trained health care workers and special education teachers. Karugu, in 1994 found that up to 50% of teachers working with students with disabilities were untrained <sup>38</sup>. There are approximately 64 ophthalmologists in Kenya for a population of 32 million (2 ophthalmologists per 1 million population). Samburu district has only 1 ophthalmic clinical officer to serve the whole population <sup>39</sup>.

Lack of funds has also made it difficult to provide grade level textbooks, maintain Braille machines and buy basic specialized equipment along with other learning and teaching materials <sup>14</sup>. The Low Vision Project, done in partnership with an NGO-Christoffel Blindenmission (CBM) has been of help in SHERP. The project provides materials such as low visual aids, special print exercise books, special desks, reading stands tape recorders, and low cost spectacles.

Samburu district has very poor infrastructure. The district has only 2 hospitals and no tarmac road <sup>40</sup>. The long distance to hospitals and poor road network has made access to health care providers extremely difficult.

#### 2.0.0 Rationale

SHERP caters for children with all kinds of handicap from all over Samburu District. Currently SHERP provides a home for the children within Maralal town but also offers itinerary services to registered children all over the district from community based contact persons. The study will provide a better understanding of the causes of eye disease and their impact on visual acuity in these children. This study will also enable us to determine the association of eye diseases and other physical anomalies in children under SHERP.

The study will form a background to other future studies in estimation of cause and magnitude of childhood blindness in SHERP.

No study to assess visual handicap and causes of childhood blindness has been done in this arid and underdeveloped part of our country.

## 3.0.0 Objectives

The main objective of the study was to determine the prevalence and pattern of eye diseases, and the association with other handicaps in children under SHERP.

The specific objectives were:

- To determine the prevalence of eye diseases in this group of children.
- Fo describe the causes of eye disease in these children.
- To find any association between eye disease and other handicaps in these children.

## 4.0.0 MATERIALS AND METHODS

## 4.1.0 Study design

A cross sectional community based study.

#### 4.2.0 Study area

Samburu district is one of the 18 districts in Rift valley province. It borders Marsabit district to the north-east; Isiolo district to the east, Laikipia district to the south. Baringo district to the south-west, and Turkana district to the north-west. The district is subdivided into 6 administrative divisions (map in appendix D). It is an arid region with an approximate area of 20626 km<sup>2</sup>, which is 3.6% of the total area of Kenya<sup>7</sup>. The whole district is served by 2 hospitals, 1 government hospital at Maralal and a mission hospital at Wamba. There are also 3 health centres, 22 dispensaries. The annual population growth rate is 2.8% and total fertility rate is 8.4 children/ woman. The whole district is served by 1 Ophthalmic Clinical Officer (OCO). Samburu district is underdeveloped, with poor infrastructure. School enrolment is low, more so in children with disability.

Samburu handicap education and rehabilitation programme (SHERP) is an NGO that was set up in 1999 and has been in the forefront of caring for children drawn from the district with handicaps, both mental and physical. Currently SHERP takes care of 87 children within its rehabilitation programme; but has registered 254 others in the entire district who get itinerary services from the community based contact persons <sup>11</sup>. SHERP provides a foster home for the disabled children. It also provides them with access to education and medical services and helps integrate the children into society. SHERP is registered as a self help group within the ministry of gender, sports, culture and social services.

### 4.3.0 Inclusion criteria

Any child (<16 yrs) registered with SHERP.

## 4.4.0 Exclusion criteria

Extremely uncooperative children who refused examination.

## 4.5.0 Instruments required.

- Questionnaires
- Snellens test types (E chart, landolt c, lea chart)
- Direct ophthalmoscope
- Indirect ophthalmoscope
- Retinoscope
- 20 dioptre loupe
- 90 d loupe
- Portable slit lamp (zeiss)
- Refraction box
- Forch
- Digital-camera
- Anterior segment camera
- Drug e.g. tetracaine 0.5%, tropicamide 1%, cyclopentolate 1%, steroid/antibiotic drops, teo, steroid drops.

#### 4.7.0 PROCEDURE

The history and ocular examination of the children was carried out as follows.

- I visited SHERP home in Maralal and the various schools in the district where children registered under SHERP are catered for.
- Introduction to the head teachers was done by the SHERP administrator, who was part of the research team.
- Consent was taken from the individual parents when available, or from the head teachers.

- Demographic data was obtained from the informants. This included details of their name, age, sex and district of origin.
- Visual acuity was then taken. Children under 4 years were assessed by the Lea chart, and the older ones by the Snellen E chart. Visual acuity was taken with best correction, if available and noted in decimal form for comparison purposes. Objective refraction under cycloplegia was done in all the children with subnormal vision (less than 6/18).
- An anterior segment examination was done with a torch and 20 Dioptre loupe.
- Where the posterior segment was accessible, dilated fundoscopy was done using the indirect ophthalmoscope and 20 Dioptre loupe. Pupillary dilatation was done using tropicamide 1%.
- Pictures of unique clinical cases were taken strictly for the purpose of the study, and only after informed consent.
- The level of visual acuity was categorized as per WHO schedule (Appendix A)
- Classification of the cause of visual impairment was done according to the anatomical site responsible. Where multiple structural anomalies were present, determination of the most significant cause of poor vision was made. Where there were different pathologies; the most preventable cause was be chosen.

#### 4.8.0 ETHICAL CONSIDERATIONS

- All data was confidential.
- Approval from the District children's officer was sought.
- Every effort was made to get consent from parents; where they were unavailable, consent was taken from the head teacher.
- All the eye drops used in the study are registered in Kenya.

- Effects of tropicamide and cyclopentolate on accommodation were explained to the parents, teachers and children.
- Children with treatable eye conditions were treated and others with complicated conditions were referred to the main hospital.

#### 4.9.0 DATA ANALYSIS

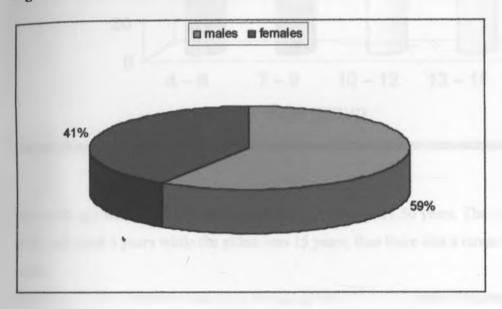
- Data was collected in the form of questionnaires and then entered into the computer awaiting analysis.
- Data validation was done before analysis.
- Analysis was done using Statistical Package for Social Scientists (SPSS) version 11.0.
- Results are presented in tables, bar graphs and pie charts.

## 5.0.0 RESULTS

## 5.1.0 DEMOGRAPHIC DATA

A total of 272 children were assessed out of a registered 341(79.76%). This was due to the fact that the children were located all over the vast district, thus it was not possible to access all of them.

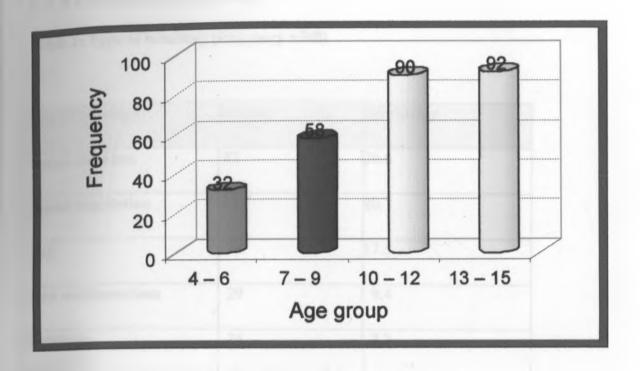
Figure 1: Sex distribution (n=272)



Of the 272 children, 161 were males and 111 were females. Males comprised 59.2% of the children. The male to female ratio was ratio 1.4:1

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Figure 2: Grouped age distribution (n=272):



The mean age was 11 with a mode of 12 and a median of 11.50 years. The youngest child was aged 4 years while the eldest was 15 years, thus there was a range of 11 years.

The majority the children came from the age group of 13 - 15 years representing 33.8% of the total number of children.

## 5. 2.0 CLINICAL FINDINGS

Table 1: Type of handicap (frequency =308)

number	percentage	
82	26.6	
64	20.7	
54	17.5	
29	9.4	
24	7.7	
13	4.2	
10	3.2	
4	1.3	
4	1.3	
4	1.3	
3	1.0	
17	5.6	
308	100	
	82 64 54 29 24 13 10 4 4 3	82       26.6         64       20.7         54       17.5         29       9.4         24       7.7         13       4.2         10       3.2         4       1.3         4       1.3         3       1.0         17       5.6

Table 2: Ocular disorders (frequency =191 eyes)

Omar disorder	Frequency	percentage
Refractive error	78	40.8
Corneal scars	32	16.8
Cataracts	10	5.2
pseudophakic	14	7.3
Eviscerated	15	7.8
Optic atrophy	14	7.3
Staphyloma	11	5.8
Squints	6	3.1
Amblyopia	5	2.6
Phthisis	4	2.1
Retinal scars	2	1.0
Total	191	100

Of the examined eyes, refractive errors were the most common finding, occurring in 78 (40.8%) eyes. 14 eyes had been operated and were pseudophakic. The eviscerations were due to traumatic eye injuries and perforated corneal ulcers.

Table 3: Prevalence of ocular disease in children with mental retardation (n=64)

Ocular lesion	frequency	percentage
Refractive errors	5	7.8
Cataract	2	3.1
Pseudophakic	2	3.1
Optic nerve atrophy	4	6.2
Corneal scars	4	6.2
Eviscerated	2	3.1
None	45	70.4
Total	64	100

19 children with mental retardation (29.6 %) had ocular disease. 6 children with cerebral palsy and 4 with Down's syndrome had mental retardation. Refractive errors were seen in 7.8% of the children (p value 0.001). Optic nerve atrophy was observed in 6.2% and this was also statistically significant (p value 0.012). Cataracts and corneal scars were each seen in 6.2% of the children. These were not statistically significant (p values 0.789 and 0.164 respectively).

Table 4: Prevalence of ocular disease in deaf children (n=54):

frequency	percentage
14	26
1	1.8
3	5.5
1	1.8
35	64.7
54	100
	14 1 3 1 35

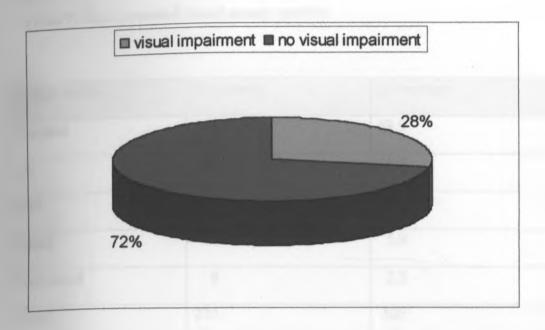
35.3 % of the deaf children had ocular anomalies. Most were due to refractive errors (26%, p value 0.003). 4 children had cataracts of whom 3 had been operated and were pseudophakic (7.3 %, p value 0.014). These were both statistically significant.

Table 5: Prevalence of ocular disease in children with other physical handicaps

Physical condition	number	Ocular disorder	number
Hemiplegia/paraplegia	37	Refractive error	11
Cleft lip/palate	10	None	0
es carinatum/ escavatum	7	None	0
Limb malformations	33	None	0
Others	17	None	0

Refractive errors were the only ocular finding in children with hemiplegia / paraplegia. This was not statistically significant (p value 0.065).

Figure 3: Visual status (n=272)



76 children (28%) had visual impairment (Visual acuity less than 6/18 in the better eye). 196 children (72%) had visual acuity greater than 6/18 in the better eye.

Table 6: Causes of visual impairment (n=76)

Deulur disease	Frequency	percentage
Refractive errors	40	52.6
Corneal scars	16	21.0
Cataracts	2	2.6
Preudophakia	10	13.1
Optic atrophy	6	7.9
Retinal scars	2	2.6
total	76	100

Table 7: Best corrected visual acuity (n=272)

Visual acuity	Frequency	percentage
Normal	190	69.9
VI	58	21.3
SVI	2	0.7
Blind	16	5.9
Not tested	6	2.2
Total	272	100

6 children had severe mental retardation and could not be conclusively assessed.

Table 8: Causes of severe visual impairment /Blindness

Cause of visual loss	Number	percentage
Corneal opacities	8	44.4
Optic nerve atrophy	6	33.3
Refractive error	2	11.1
cataracts	2	11.1
Total	18	100

Corneal opacities accounted for most of the causation of blindness. This is a

preventable cause of blindness. Both cataracts and refractive errors are treatable.

Thus, avoidable blindness comprised 66.6 % of the cases.

## 6.0.0 DISCUSSION

A total of 272 children (161 males and 111 females) were examined. SHERP has a total registered population of 341 children. Thus 79.76 of the children were examined. The children are located in various parts of the district and due to its vast size (20626km²) it was not possible to access all the children during the study.

#### 6.1.0. DEMOGRAPHICS

Most of the children were male (Figure 1) with a male: female ratio of 1.45: 1

The male: female population ratio in the district, as per the 1999 population census is 1:1. None of the conditions found (Table 1) are known to be X linked. This discrepancy could be due to the fact that disability grossly hampered the core duty of males; walking long distances tending livestock and thus were more likely to be deemed a liability and rejected by the family. It is also likely that despite some handicaps, girls could still be able to perform some home based activities thus were less likely to be rejected by the family.

SHERP was started 7 years ago and most of the older children at the centre were picked when younger, at about 4 or 5 years. Most of the older children had been in the SHERP programme since its inception. This explains why majority of children were aged between 10 and 15 years (Figure 2). The youngest child was aged 4 years. This could be because most of the conditions were only noticed when the children were older, at 3 to 5 years. This includes conditions like deafness, mental retardation and severe refractive errors.

Some conditions could also be acquired in early childhood (2-4 years) and this is when the children were rejected by the families. This includes blinding conditions like corneal scarring secondary to ocular trauma, infectious corneal ulcers and VAD

#### 6.2.0 CLINICAL FINDINGS

#### 6.2.1 FAMILY HISTORY

A positive family history of similar eye disease or physical anomaly was found in only 5% of the children. This was because most children did not have records and parents were not available and not necessarily because inherited or familial conditions were rare. When children are assessed and registered in SHERP, no medical examination is done and often the social- demographic information is not recorded. The few children from whom family history was available were those we visited at their manyattas.

#### 6.2.2 TYPES OF HANDICAP

Ocular disorders comprised the majority of handicaps; occurring in 82 children (Table 1) this was followed by mental retardation in 64 children and deafness in 54 children. There were 66 children with various limb anomalies, mainly due to neurological disease. The higher number of children with ocular disorders was due to the fact that some of the children with other types of handicap had coexisting eye disease. These were added to the number of children who were brought to SHERP with primarily eye disease e.g corneal blindness. Most of the paraplegics were due to polio and associated neuronal problems. Kenya expanded programme for immunization (KEPI) reports of 1998-2003 indicate that the oral polio vaccine (OPV) coverage rate for Samburu district was 42%.

This coverage rate was very low, thus many children remained unimmunized and prone to polio associated paraplegia. The rate was also much lower than the national average of 59% during the same time, and could explain the higher polio associated paraplegia.

There were 64 children with mental retardation. Mental retardation was inferred on the basis of onset under 18 years of age and presence of low intellectual functioning. This was evidenced by impairment in self care, school work, social behaviour, and communication skills. Ideally, an IQ test should also have been performed to confirm mental retardation and classify it into mild, moderate, severe and profound as per the diagnostic statistical manual (DSM IV classification). The IQ test was not done and it is likely that some normal children could have been classified as mentally retarded. There were 4 children with Down's syndrome and all had mental retardation. All had strabismus, with esotropia occurring in 3 of the children. Other findings seen in all the children were slanted canthi, nystagmus and epicanthic folds. 2 children had refractive errors (1 myope and 1 hypermetrope). No Brushfield spot was noted. The numbers in this study was very low thus it is difficult to compare with other studies and draw conclusions. Nevertheless, other studies have shown high rates of ocular anomalies in children with Down's syndrome. da Cunha et al examined 152 children with Down's syndrome and found that 82% had slanted canthi, 38% had strabismus, and 38% had astigmatism <sup>22</sup>. Kim et al examined 123 children and found that 61% had epicanthic folds, 53% had refractive errors and 22% had nystagmus <sup>24</sup>.

## 6.2.3 TYPES OF OCULAR DISORDERS

Most of the ocular disorders were due to refractive errors (Table 2). Most of these children did not have their optical correction as they had never been assessed by an eye care worker. No child was registered under SHERP due to refractive errors; rather, the refractive errors were noted in children with other anomalies. Of the 76 children with visual impairment, refractive errors were the main cause in 40 (52.6%). This probably reflects the general trend that refractive error is one of the commonest ocular anomalies in this age group. Nzuki in an MMed thesis of 2004 found a prevalence of refractive errors of 10.2%.

Corneal scars, eviscerated eyes and staphylomas were also very common, comprising 17%, 8% and 6% of the ocular anomalies respectively. These were mainly due to trauma and corneal ulcers. No Bitot spots were seen and enquiry about night blindness was made in all children with corneal lesions. It is likely that there was a very low incidence of VAD in the community due to the diet comprising mainly animal products like meat, liver, blood and milk. The high number of corneal scars due to trauma probably reflects the pastoralist activities of herding for males and firewood collection for the females. The high numbers of eviscerated eyes was likely due to traumatic eye injuries or poorly managed corneal ulcers complicated with perforations.

# 6.2.4 ASSOCIATION OF OCULAR ANOMALIES WITH OTHER HANDICAPS

35.3% of deaf children had ocular disorders (Table 4). Refractive errors occurred in 26% and cataracts in 7.5% of the children.

Studies done elsewhere also show higher rates of ocular anomalies in deaf compared to normal children. Leguire et al studied 505 deaf children and found that 48.7% had ocular anomalies <sup>26</sup> while Elango et al examined 165 deaf children and found 57.6% with ocular anomalies <sup>27</sup>.

Hanioglu et al examined 104 deaf children and found that 40.4% had ocular anomalies, 30% of which were refractive <sup>28</sup>. In this study 54 children were examined and probably the smaller sample size compared to the other studies accounted for the lower percentage of deaf children with ocular disorders.

Ocular anomalies were seen in 29.6% of children with mental retardation (Table 3). There were significant differences in the findings of this study compared to other published studies. Mwanza et al examined 73 mentally retarded children in Zaire and found that up to 60% had ocular disorders. He showed that 21.7% had eyelid anomalies, 21.7% had fundus anomalies and 15% had refractive errors <sup>31</sup>. This could be attributed to the fact that this study had relatively fewer study subjects and differences in definition of mental retardation. The definition of a mentally retarded child requires assessment of IQ and since this was not done in this study, it is likely that some children who were not mentally retarded, (i.e. normal) were included in the subgroup, thus the lower prevalence of ocular anomalies

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Most of the children with paraplegia/ hemiplegia did not have any ocular pathology except for refractive errors, which occurred in 11 of 37 children (33%). In the 40 children with refractive errors, 2 were not fully correctable, and in the absence of any obvious pathology, were diagnosed as amblyopic.

The occurrence of refractive errors in the children with neurological limb anomalies was not statistically significant and this was likely to have been a chance finding reflecting the common occurrence of refractive errors in all populations.

#### 6.2.5 CAUSES OF SVI/BLINDNESS

Corneal scars were the most significant cause of SVI/Blindness (V.A< 6/60). These were likely due to improperly managed corneal ulcers and trauma. This corroborates the finding in many childhood blindness studies as shown in the WHO global data on blindness which show that blindness in developing countries mainly involve the anterior segment and are wholly preventable.

6 children had optic nerve atrophy, high refractive errors and cataracts occurred in 2 children each. It was not possible to determine the cause of the relatively high numbers of children with optic atrophy.

#### 6.3.0 LIMITATIONS OF THE STUDY

- 1. Due to the large size of the district, it was not possible to assess all the children and achieve the desired target of 90-100% coverage.
- 2. The assessment of mentally retarded children was not as per the recognized DSM IV classification since IQ tests were not done thus standardisation with other studies was impossible.
- 3. The actual numbers of deaf and mentally retarded children was small compared to other studies thus making comparisons was difficult.

## 7.0.0 CONCLUSIONS

- 1. There is a high prevalence of ocular anomalies (28%) in handicapped children in SHERP.
- 2. Refractive errors are the commonest eye condition causing sub optimal vision (worse than 6/18).
- 3. The commonest cause of severe visual impairment and blindness is corneal scars.
- 4. Mentally retarded and deaf children have high rates of ocular anomalies, mainly refractive errors.

#### 8.0.0 RECOMMENDATIONS

- 1. Screening for ophthalmic problems in deaf and mentally retarded children should be done as soon as the conditions are diagnosed, irrespective of age, to enable early intervention.
- 2. There is need for proper record keeping in SHERP. This should include complete demographic details, medical and family social history.
- 3. Refractive errors are very common in children registered under SHERP and low cost, durable spectacles should be supplied to these children.
- 4. Studies should be done in both schools for the deaf and mentally retarded involving larger sample sizes to shed more light on ocular disorders in these children.

# **APPENDIX A:**

# Plate 1.



Child with limb anomalies, no ocular features

Plate 2



Child with corneal scar RE and eviscerated LE

## **APPENDIX B**

#### WHO CLASSIFICATION OF VISUAL ACUITY

Low vision comprises categories 1 and 2

Blindness comprises categories 3, 4, 5.

Patients with a field no greater than 10° but greater than 5° around central fixation should be placed in category 3 and patients with a field no greater than 5° around central fixation should be placed in category 4, even if the central acuity is not impaired.

CATEGORIES	BCVA	
	Maximum less than	Minimum equal or better
		than
1.visual impaired	6/18	6/60
2. severe visual	6/60	3/60
impairment		
3. blindness	3/60 or visual field less	1/60 or visual field greater
	than 10 degrees	than 5 degrees
4.	1/60 or visual field less	Light perception
	than 5 degrees	
5.	No light perception	

### **APPENDIX C**

#### **CONSENT EXPLANATION**

Title of project: "Ocular findings among children in Samburu handicap education and rehabilitation programme."

I Dr Victor Njom would like to give you information on the study titled "Ocular findings among children in Samburu handicap education and rehabilitation programme"

#### AIMS:

The study will be conducted on all the children registered under SHERP. The study aims to assess the prevalence of visual problems in the children and also to find out the main causes of visual disability in the children.

#### EYE EXAMINATION

I will take a short history concerning the child, after which I will take the visual acuity. I will then do a complete eye exam with a torch and magnifying loupe. I will use dilating drops to facilitate fundoscopy. These drugs will cause a transient blurring of vision.

I will inform the parents of the visual outcome and advice accordingly.

#### **CONSENT FORM**

I agree as the parent/ administrator/ head teacher to participate in the study on the prevalence and pattern of eye diseases in children in the SHERP programme in Samburu district to be carried out by Dr. Njom Victor from the University of Nairobi who is the principal investigator, whose aim is to find out the prevalence and pattern of eye diseases, affecting the children under the care of SHERP programme.

The principal investigator has explained to me the transient side effects of the dilating drops on the children.

I understand that the results from this study will be used to formulate a programme on how best to address the eye diseases afflicting the children and may go towards planning and administration of better primary eye care to the district as a whole.

It has been explained to me that all the data collected will be treated in the strictest confidence and will not be disclosed to any persons not party to the study. It has also been explained to me that our participation in the study is voluntary and at any point in the study any child who so wishes to withdraw his or her participation will be allowed to do so voluntarily without victimisation.

I am free to ask any questions to the principal investigator at any point during the data collection period.

Signed	Parent/Adminstrator/Headteacher
Date	
Signed	Principal Investigator Date

# APPENDIX D

## **QUESTIONNAIRE**

PERS	SONAL	<b>DETAILS</b>						
Name	e					Number		
Home district				Age (y	rs)			
Sex (	M/F) _							
Age a	at onset	of visual los	SS					
Fami	ly Histo	ry: Anyone	in family	with simil	ar condition?			
				If yes,	who?			
VISU	JAL AS	SESSMEN	Γ					
Far v	ision: w	ith glasses		Unaid	led			
			RE		LE	BE		
6/6- (	6/18							
Less	than 6/	18-6/60						
Less	then 6/0	50-3/60						
Less	than 3/6	60 – PL						
No li	ght per	ception						
Cann	ot be te	sted						
PRE'	VIOUS	EYE SURG	ERY					
Eye	None	glaucoma	cataract	Corneal	Optical	removed	Unknown	others
				graft	iridectomy		surgery	
RE								
LE								

EYE EXAM- site of ABNORMALITY leading to visual loss

For each eye mark one major abnormality and others contributing to visual loss

## Whole globe

EYE	phthisis	anopthalmos	microphthalmos	buphth	glaucoma	removed	disorgan	others
RE								
major								
RE								
Others								
LE								
Major								
LE								
Others		E						

#### Cornea

eye	staphyloma	scar	Keratoconus	dystrophy	Other opacity
RE Major					
RE Other					
LE Major					
LE Other					

## Lens

Eye	cataract	aphakia	Other
RE Major			
RE Other			
LE Major			
LE Other			

# Uvea

Eye	aniridia	coloboma	Uveitis	other
RE Major				
RE other				
LE Major				
LE Other				
	1			

#### Retina

eye	dystrophy	Albinism	rop	rtb	other	Optic.n atrophy	Optic n hypoplasia	others
RE								
Major								
RE								
Other				:				
LE								
Major								
LE								
Other		181						

## Others- If globe appears normal, do OR/ SR

Eye	Refractive	amblyopia	Cortical	Idiopathic
	error		blindness	nystagmus
RE Major				
RE Other				
LE Major				
LE Other				

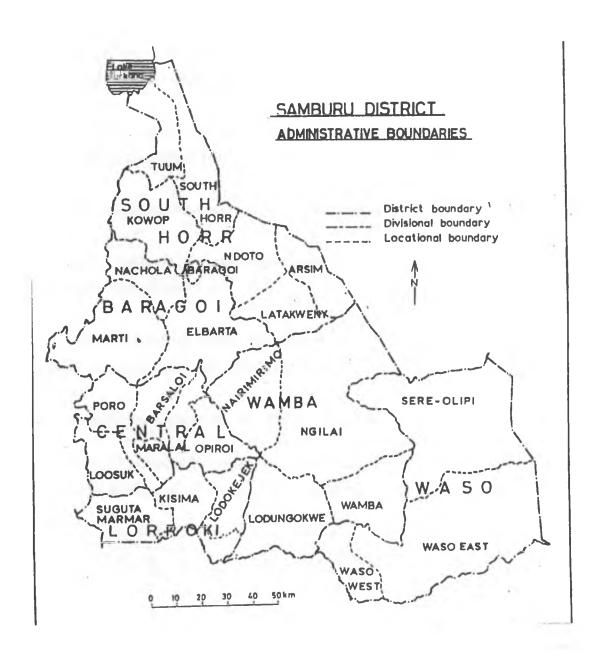
Other disabilities
Physical
Mental
Normal children (if so state reason, for being in this school)

## EYE EXAMINATION- AETIOLOGY OF VISUAL LOSS

1. Hereditary disease
Autosomal
X linked
Cannot specify
2. Intrauterine factor
Rubella
Toxoplasmosis
Drugs/alcohol
Others
3. Perinatal / neonatal factors
Cerebral hypoxia
Retinopathy of prematurity
Other
•
4. Postnatal / infancy/ childhood factor
Vitamin A Def
Measles
Neoplasms
Trauma
Traditional Practises
Other
5. Cannot determine-
Abnormal Since birth
Retinoblastoma (no family history)
Glaucoma/ buphthalmos
Other

## APPENDIX E

#### MAP OF SAMBURU DISTRICT



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#### REFERENCES

- 1. Mclaren D S. Childhood blindness a review and a caveat. Medicine Digest 1991; June 3-9
- 2. World Health Organization, Geneva. Global initiative for the elimination of avoidable blindness. Geneva WHO/PBL/97.61.
- 3. Thylefors B, Negrel A D, Pararajasegaram R. et al. Global data on blindness. Bull. World health organization 1995; 73:115-121
- 4. Clare G, Foster A. Childhood blindness World Health magazine 1995; 48 (5): 5-6
- 5. Clare G. Childhood blindness: Major causes and strategies for prevention. Comm. Eye health. 1993; 12 (6):16-17
- 6. Njuguna M. Aetiology of childhood blindness among children in schools for the blind in Kenya. (Mmed thesis 2000) unpublished.
- 7. Population census atlas of Kenya. 1999 by Central Bureau of Statistics.
- 8. Ezegwui I R, Umeh R E, Ezegue U F. Causes of childhood blindness: Results from schools for the blind in S.E. Nigeria. Brit J. Ophthalm. 2003; 87: 20-23
- 9. Maino D M, Rado M F, Pizzi W J. Ocular anomalies of individuals with mental illness and dual diagnosis. : J Am Optom Assoc. 1996 Dec; 67(12):740
- 10. Nikolopoulos T P, Lioumi D, Stamataki S et al. Evidence based overview of ophthalmic disorders in deaf children: A literature update.

  Otol. Neurol 2006 Feb; 27 (2 suppl 1): s1- 24
- 11. Bothe N, Lieb B, Schafer W D. Development of impaired vision in mentally handicapped children. Klin. Monatsbl Augenheilkd 1991 Jun; 198 (6): 509-514.

- 12. McLinden M, Children with multiple disabilities and visual impairment. London. David Fulton publishers. Pg 13-15
- 13. Mason H L, Spotlight on special educational needs. (1995) Tamworth. Nasem publications. Pg 5
- 14. Waihenya K, 8-4-4 locks out disabled children. International journal of special education 2004, Vol. 19, No. 2
- 15. Kalter H, Warkany J. Congenital malformations. N Engl J Med 308:424, 1983
- 16. Rudolph AJ, Desmond MM: Clinical manifestations of the congenital rubella syndrome. Int Ophthalmol Clin 12:3, 1972.
- 17. Fairgrieve SD, Jackson M, Jonas P, et al: Population based prospective study of the care of women with epilepsy in pregnancy. BMJ 321:674-5, 2000
- 18. Stromland K .Visual impairment and ocular abnormalities in children with fetal alcohol syndrome. Addict. Biol. 2004 Jun; 9 (2): 159-160
- 19. Siegel M, Fuerst H T, Guinee V F. Rubella epidemicity and embryopathy: Results of a long term prospective study. Am. J. Dis. Child.1971; 121: 469
- 20. Khandakar R, Al Awaidy S, Ganesh A et al. An epidemiological and clinical study of ocular manifestations of congenital rubella syndrome in Omani children. Archives of ophthalmology.
- 21. Hook EG. Epidemiology of Down syndrome. In Pueschel S, Rynders JE (Eds). Down syndrome. Advances in Biomedicine and the Behavioural Sciences. Cambridge: Ware Press, 1982:11
- 22. da Cunha R P, Moreira J B. Ocular findings in Down's syndrome. Am. J. Ophthalm. 1996 Aug; 122 (2): 236-244

- 23. Berk A T, Saatci A O, Ercal M D. Ocular findings in 55 patients with Down's syndrome. Ophthalmic. Genet. 1996 Mar; 17(1): 15-19
- 24. Kim J H, Hwang J M, Kim H. Characteristic ocular findings in Asian children with Down's syndrome. Eye. 2002 Nov. 16 (6) 710-714
- 25. Bodenmueller M, Goldblum D, Frueh B E. Penetrating keratoplasty in Down's syndrome. Klin. Monatsbl. Augenheilkd 2003 Mar. 220 (3):99-102
- 26. Hanioglu S, Koksal M, Tomac S. et al. Ophthalmologic abnormalities in children from a Turkish school for the deaf. Turk. J. Pediatr. 2003 Jan-Mar; 45(1):39-42
- 27. Leguire L E, Fillman R D, Fiahman D R. et al. A prospective study of ocular abnormalities in hearing impaired and deaf children. Ear Nose Throat J. 1992 Dec; 71(12): 643-646
- 28. Elango S, Reddy T N, Shriwar S R. Ocular abnormalities in children from a Malaysian school for the deaf. Ann. Trop. Paediatr. 1994; 14(2):149-152
- 29. Nicoll A M, House P. Ocular abnormalities in deaf children: A discussion of deafness and retinal pigment changes. Aust. N Z. J Ophthalmol. 1988 Aug; 16(3): 205-208
- 30. Haire A R, Vernon S A, Rubinstein M P. Levels of visual impairment in a day centre for people with mental handicap. J R Soc. Med. 1991 Sep; 84 (9): 542-544
- 31. Mwanza J C, Nkidiaka C M, Kayembe D L, et al. Ophthalmologic abnormalities in mentally retarded. Bull. Soc. Belge Ophthalmol. 2000; (272):75-78
- 32. Goto S, Yo M, Hayashi T. Intraocular lens implantation in severely mentally and physically handicapped patients. Jpn J Ophthalmol. 1995; 39(2): 187-192

- 33. Gilbert C, Foster A, Negrel A D. et al. Childhood blindness; A new form for recording causes of visual loss in children. Bull. World Health Org. 1993; 71 (5): 485-9
- 34. Smith A F, Smith J G. The economic burden of global blindness: a price too high. Br. J Ophthalmol. 1996; 80: 276-277
- 35. Shamanna B R, Dandona L, Rao G N. Economic burden of blindness in India. Ind. J Ophthalmol. 1998; 46:169-172
- 36. Aaby P, Samb B, Simondon F. Non specific beneficial effect of measles immunisation: analysis of mortality studies from developing countries. 1995; BMJ, 311, 481-485.
- 37. Barclay A J G, Foster A, Sommer A. Vitamin A supplements and mortality related to measles: a randomized clinical trial. 1987; BMJ, 294, 294-296
- 38. Karugu G K, Special education trends and issues in relation to teacher education curriculum. A paper presented at the third teacher education seminar at Egerton University, Nov. 1994
- 39. The Kenya ophthalmic programme. Fourth five year development plan. 1997-2002 Pg 33
- 40. Report on poverty in Kenya. Welfare indicators volume 3, 2000 Central bureau of statistics. Ministry of finance and planning. Pg 8
- 41. SHERP. Annual report 2005. Pg 5

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