

Presidential Address – 2021

Overcoming blindness from womb to tomb

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I am privileged to deliver this address in December; the month in which a day is named as the “International Day of Persons with Disabilities”. Every year the 3rd of December is dedicated to highlighting the challenges disabled persons face due to unequal opportunities, discrimination and lack of empathy. This day is also about promoting the rights and well-being of persons with disabilities.

Living with disability

The global magnitude of disability is immense. It is known that approximately 15% of the total world population, amounting to more than one billion people, live with some form of disability (Figure 1). When considering the Sri Lankan perspective, as per the last population census conducted in 2012, the number of persons with disabilities living in Sri Lanka constituted 8.7% of the population. Numerically nearly 1.6 million Sri Lankans above the age of 5 years, live with some form of disability (Figure 2). It has been stated in the census that females had a higher incidence of disability when compared to males. The disability most relevant to us, as ophthalmologists is vision impairment and blindness (Sri Lankan perspective and world disability).

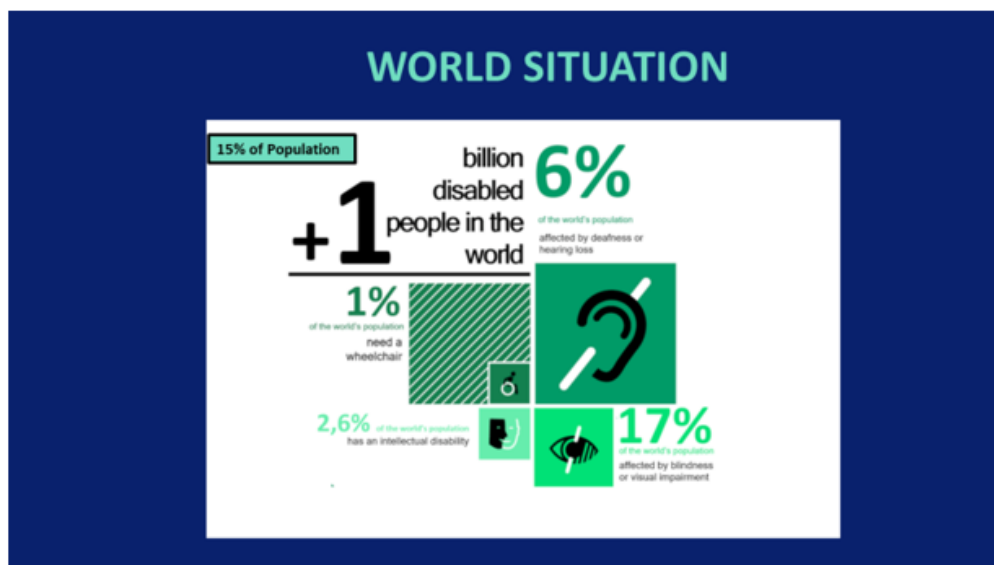


Figure 1.

Vision impairment and blindness

Knowledge of the physical world around us is obtained through our senses. The simple joys of life, how do we ‘see’ them? The credit for this wondrous perception goes to the most important sensory organ of the body, the eyes. Our eyes introduce us to the light of this beautiful world. Sight is the most vital and precious sensation we experience as human beings. Loss of sight is one of the greatest misfortunes that can befall a human being.

¹Consultant Ophthalmologist – The President, College of Ophthalmologists of Sri Lanka, 2021.

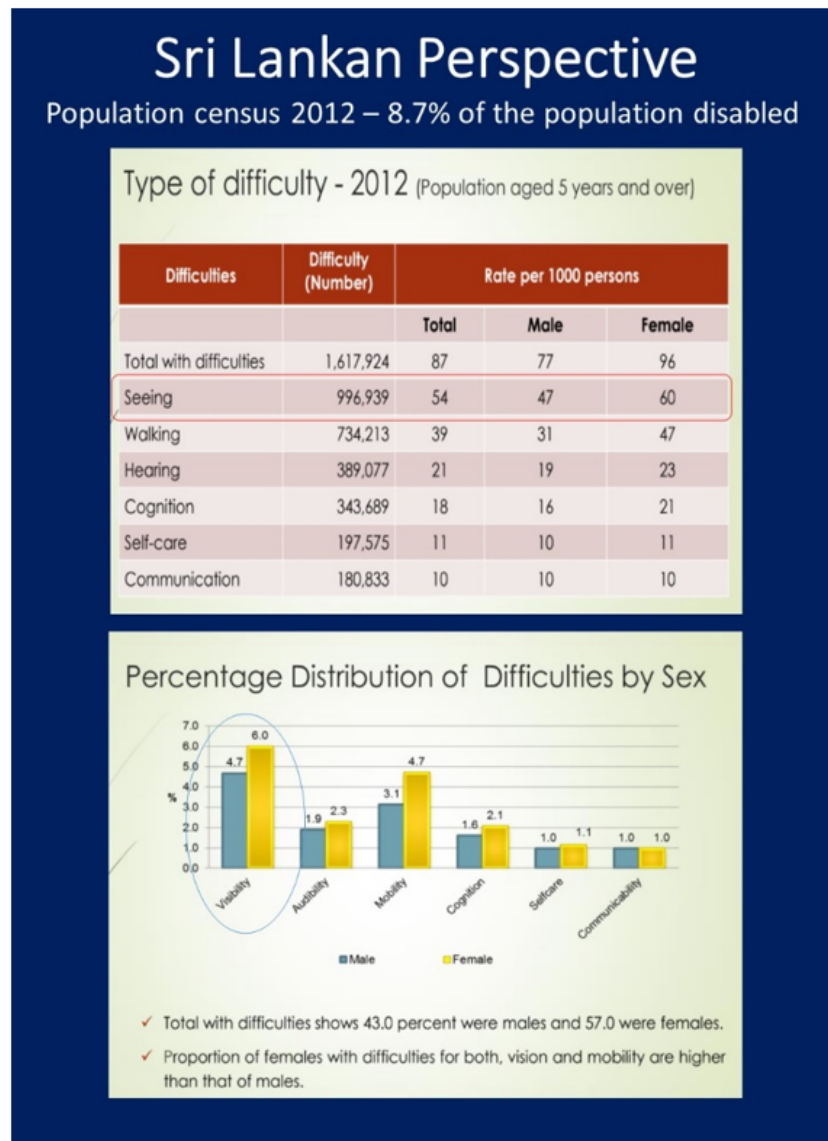


Figure 2.

Blindness is defined by the World Health Organization as vision in a person's better eye with best correction of less than 3/60 or a visual field of less than 20 degrees. Vision impairment, although less well defined encompasses a broad spectrum of vision levels, ranging from mild distance and near vision disability to total blindness (Figure 3). As a whole, 17% of the world population is affected by blindness and visual impairment and its prevalence is on the rise. This is due to a rise in the ageing population globally, and the worldwide increase in non-communicable and chronic diseases. Looking at the global indices, out of the world's population, 36 million people are blind, and 217 million people suffer from Severe Visual Impairment. Of this, 89% of visually impaired people live in low and middle income countries. Alarming, the number of blind people worldwide is estimated to increase to 115 million by the year 2050.

Congenital or acquired blindness affects life in many ways. It often causes a negative impact on families, affects livelihoods and deprives opportunities in education and socio-economic development. In countries where the infrastructure is not friendly for those without sight, the affected person often ends up being dependent, and living an undignified life.

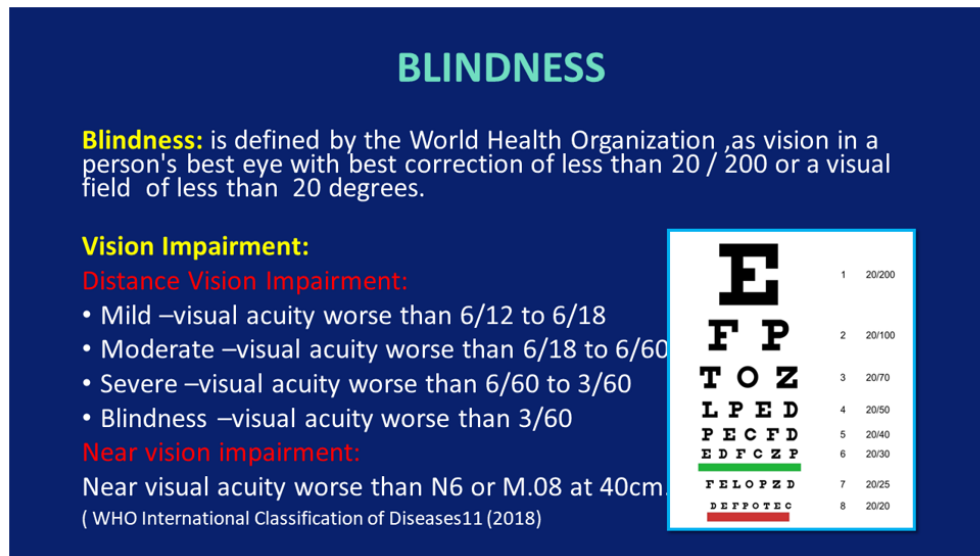


Figure 3.

Blindness in childhood

When considering childhood blindness and vision impairment, a wide regional variation is observed in the causative factors. Globally, the majority of early vision loss is either preventable or treatable. The commonest causes for childhood blindness vary, depending on the income levels of the country. In countries with higher income levels, common causes would include genetic factors, retinal disorders related to prematurity and neurological diseases which require intervention at a tertiary level. In low income countries much of the vision loss is associated with infections and nutritional deficiencies, where prevention is largely at primary care level (Figure 4).

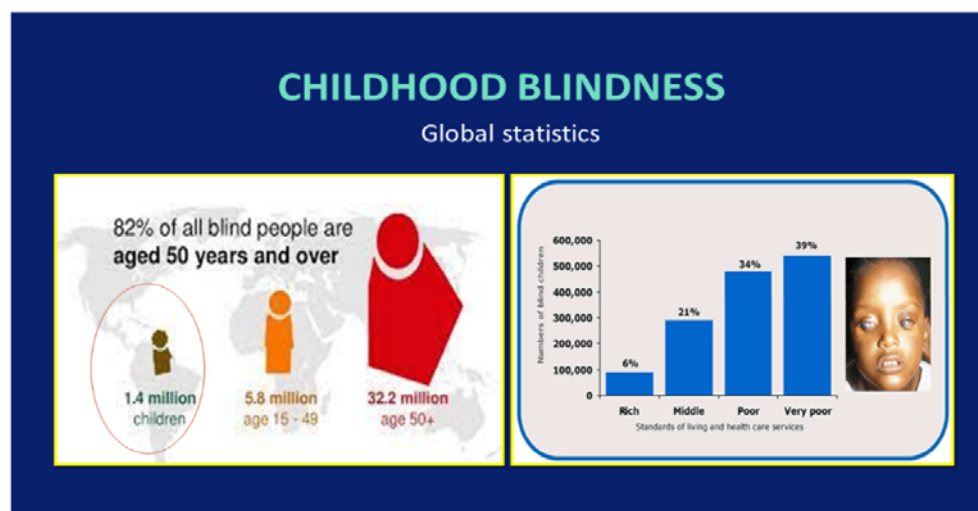


Figure 4.

Childhood blindness in Sri Lanka

The pattern of childhood blindness in Sri Lanka has evolved over several decades, as shown by the pioneering studies conducted by eminent ophthalmologists in the country. Two of the earliest landmark studies on the subject of childhood blindness were conducted and published in 1944 and 1966 respectively by De Silva and Ruby Pararajasekaram. Pararajasekaram at the conclusion of her Presidential Address in 1966, commenting on her study, stated that an attempt has been made to obtain a pattern of blindness of children in Ceylon. The study represented a fair cross section of the blind child population. The redeeming feature is the fact that the incidence

of malnutrition and infections, as the leading cause of blindness has dropped, since the original report of De Silva in 1944 and this trend has continued in the last decade too.

A study done almost three decades later in 1995 analyzing the causes of childhood blindness in children attending six blind schools showed a different trend in the aetiology when compared to the study done in 1966. According to the 1995 study it was found that cataract was the commonest reversible cause of childhood blindness among children studying in these blind schools of Sri Lanka. Irreversible etiologies such as hereditary diseases of the retina, lens, and optic nerve, were responsible for one third of all admissions to blind schools. Vitamin A deficiency which was more commonly seen in the initial studies, was now rarely seen and was only limited to certain communities.

A more recent study done in 2011, a survey done in thirteen blind schools showed that of the irreversible causes of childhood blindness the majority were unknown or showed hereditary causes. Retinopathy of prematurity made up the largest proportion of avoidable causes. An analysis of this changing pattern of etiologies showed that in Sri Lanka, the pattern had changed from intrauterine infections and nutritional causes being a leading cause of childhood blindness seven decades ago, to a current pattern more closely resembling that of a higher income country i.e. hereditary causes and ROP. This achievement could be attributed to an advancement in primary health care together with an ever increasing level of education of pregnant females on all aspects of nutrition and health. Additional nutritional supplements given to expectant mothers and an improvement of ante natal care services also helped in changing the trend from that of a low income country to the present pattern that we see.

The role of vaccination in the prevention of childhood blindness

The prime reason for the etiological pattern change has been attributed to the success of our immunization program. The efficient coverage of immunization against measles and rubella being the key factor. Rubella infection in pregnancy affects the eye in many ways. It can cause congenital cataract, corneal opacities, microphthalmos and pigmentary retinopathy. Rubella vaccination alone effectively prevents all these disabilities. The vaccination coverage in the country has been consistently high – over 95% with both the first and second second dose of measles and rubella vaccine provided to children under the routine immunization programme.

In the year 1996, Sri Lanka introduced rubella vaccination for women aged 16-44 years, in an attempt to eliminate congenital rubella syndrome. Furthermore, in 2001 the measles-rubella vaccine was introduced as a component of the routine immunization schedule. To further strengthen the program, the Ministry of Health of Sri Lanka in 2017 defined the steps to be taken to eradicate rubella and measles from the country. On the 9th of July 2019, WHO declared that Sri Lanka has eliminated measles, interrupting transmission of the indigenous virus that causes the killer childhood disease. Also more than 20 years of routine rubella vaccination had resulted in a 96% reduction in reported rubella cases and a corresponding 98% reduction in CRS cases. In 2020 Sri Lanka was verified for having eliminated rubella, making us one of the first two countries in WHO South-East Asia Region to achieve measles and rubella elimination ahead of the 2023 target.

Impact of rubella vaccination on elimination of congenital rubella syndrome in Sri Lanka: progress and challenges

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ABSTRACT

Rubella infection in pregnancy can lead to pathologies, including miscarriage, stillbirth and congenital rubella syndrome (CRS) in the neonate. Rubella vaccination can prevent all occurrences of CRS. In Sri Lanka, significant outbreaks of CRS occurred in 1994 and 1995, with 275 and 212 reported cases. In 1996, Sri Lanka introduced rubella vaccination for women aged 16–44 years, to stop CRS. Measles–rubella vaccine was introduced into the routine immunization schedule in 2001 and additional campaigns were carried out in 2003 (all 11–15 year olds) and 2004 (all 16–20 year olds). Reported immunization coverage with a single dose of a rubella-containing vaccine has been more than 95% since 2000. Laboratory-supported surveillance for rubella and CRS was started in 1992. Reported rubella cases fell from 364 (incidence 19/million population) in 1999 to 96 cases (incidence 5/million population) in 2002 and further to 12 cases (incidence 0.6/million population) in 2014. Laboratory-supported CRS surveillance was started in 1990 and the highest number of CRS cases, 275 (incidence 77/100 000 live births), was diagnosed in 1994. Reported CRS cases fell from 22 cases (incidence 7/100 000 live births) in 2002 to 3 cases (incidence <1/100 000 live births) in 2014.

Almost 20 years of routine rubella vaccination has resulted in >96% reduction in reported rubella cases and a corresponding >98% reduction in CRS cases. Despite this great achievement, work remains to eliminate rubella and CRS from Sri Lanka.

Key words: congenital rubella syndrome, elimination, rubella-containing vaccine, rubella vaccination, Sri Lanka

Rubella is a mild disease affecting children and adults. However rubella in pregnant women is important as the virus is transmitted to the foetus across the placental barrier, sometimes with significant teratogenic effects. Rubella vaccine was introduced into the National Immunization Programme in 1996, targeting all reproductive age females of 11-44 years, with the objective of preventing congenital rubella syndrome (CRS). This was carried out as a school based programme by giving rubella vaccine to all children aged 11-15 years, and vaccinating the rest at the community clinics. Number of measles and CRS cases have markedly reduced and surveillance of measles, rubella and CRS was strengthened in 2005-2010 under the plan of 'intensification of the surveillance and Laboratory confirmation was made available for all suspected cases of Measles, Rubella and CRS from there to date.

Acceleration of measles, rubella, CRS Elimination Plan 2017-2020

In par with the Regional Measles, Rubella and CRS elimination strategic plans, Sri Lanka has set the goal of elimination of Measles, Rubella, CRS by 2020.

Vision: Sri Lanka is free from measles, rubella and CRS

Goal: To achieve and sustain measles, rubella and CRS free status in Sri Lanka

Objectives: To achieve and maintain zero endogenous transmission of measles, rubella and CRS in Sri Lanka and identify and contain possible imported outbreaks

Elimination targets:

- Zero endogenous measles cases by 2020
- Zero endogenous rubella cases by 2020
- Zero CRS case/ 100,000 live births by 2018

Components of elimination strategies:

- Achieve and maintain high levels of population immunity by providing two doses of measles and rubella containing vaccines with high vaccination coverage
- Strengthened disease surveillance including laboratory confirmation of all suspected cases of measles, rubella, CRS cases: case based investigation
- Strengthen country preparedness for outbreak prevention and response : contain outbreaks early
- Adequate patient care management to prevent the transmission and mortality
- Perform research to generate evidence for cost effective implementation strategies for measles , rubella, CRS elimination

Measles and Rubella vaccination

- All eligible children who have completed the age of 9 months and the age of 3 years are to be vaccinated with MMR vaccine according to the current National Immunization schedule in Sri Lanka

Hereditary blindness and consanguinity

An analysis of hereditary blindness, showed the causative factors to include consanguineous marriages, giving rise to congenital anomalies. A study done on marriage patterns in Sri Lanka and the role of consanguinity in patients with thalassaemia; showed the national consanguinity rate to be 7.4%. Another study on cousin marriages of South Asia revealed that the North of Sri Lanka had a higher rate of consanguinity of 22.4% (Figure 5).

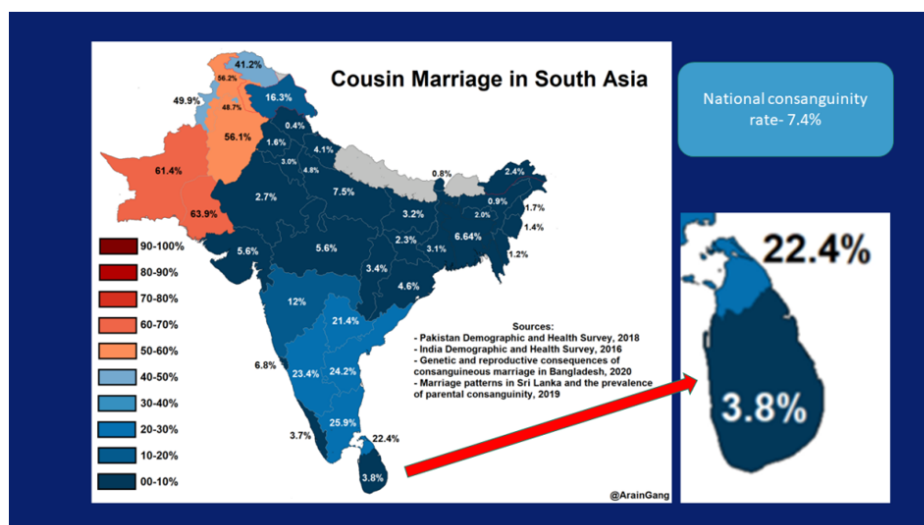


Figure 5.

Educating the blind

What is the fate of children who are irreversibly blind or have significant visual impairment at birth or in early childhood? Educating and teaching special life skills are the keys to their subsequent acceptance into society. In this aspect we are proud that Sri Lanka has a long and successful history of educating the blind.

The premier institute involved in educating children with special needs in Sri Lanka is the School for the Deaf and Blind, Ratmalana which was started more than a century ago in 1912. There are currently seventeen schools for the visually impaired in Sri Lanka. A code of regulations for blind schools, was first published in 1979 in order to maintain a uniform standard among all the blind schools scattered across the country.

A program of inclusive education for the vision impaired commenced in 1969 under the aegis of the Ministry of Education, and continues even up to date. This provided an opportunity for these special children, to be educated in a normal school environment. In keeping with the trend of inclusive education that was already being followed in Sri Lanka, a worldwide international policy on the education of all disabled children known as the Salamanca Statement was signed in Spain in 1994. Sri Lanka too became a signatory endorsing a practice that had been carried out here for more than 25 years. This called for inclusion to be the norm. The guiding principle of which is that ordinary schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions (Figure 6).



Figure 6.

Methods of educating blind children

In Sri Lanka, the blind community is mainly one of Braille readers. Braille has been the primary medium of information and instruction, since the commencement of education for the blind in the country. Other modes of education available at present are talking books, special computers and technological aids for reading print.

In 1966, the Sri Lanka Council for the Blind, commenced the production and distribution of talking books. Since 1980, the Government of Sri Lanka has been providing school textbooks free of charge to sighted students, but the service was not available to blind students at that time. However in 1985, a Braille press was established at the National Institute of Education, Maharagama. Here Braille versions of the textbooks, recommended by the Department of Education were published. This further strengthened the concept of free inclusive education for children with special needs that had commenced almost 20 years before (Figure 7).

Inclusive education in the presence of a disability

Inclusive education is a child's right and not a privilege. The benefit that an inclusive education bestows on a child with disability are enormous. However inclusive education is not without its drawbacks some of which I have noted below (Figure 8).

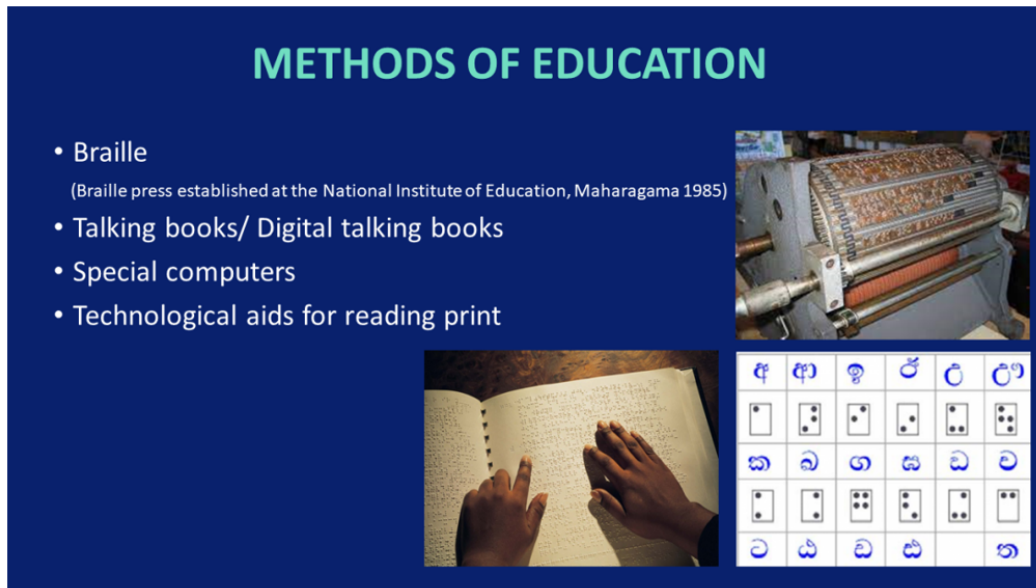


Figure 7.



Figure 8.

It is to be highlighted the fact that as far as sporting activities are concerned, sports which a blind student in inclusive education can do amongst sighted children are limited. I quote from a paper article which captured my attention, written by R S N Karunaratne, a person with severe vision impairment, who learnt in the inclusive education stream and is now employed as a teacher. She states "The physical education period was my worst nightmare, on one hand because the instructress called me derogatory names, and on the other hand, I could not engage in the activities and had to watch my friends have all the fun". This seemed to have been the sad state of affairs prevalent in the education institute she was attached to as a child. Enhancing the system for the benefit of these special children has to be undertaken by the key resource persons involved in their education. They are namely the school teacher, the school administrator or principle, peers, parents, family and the community (Figure 9).

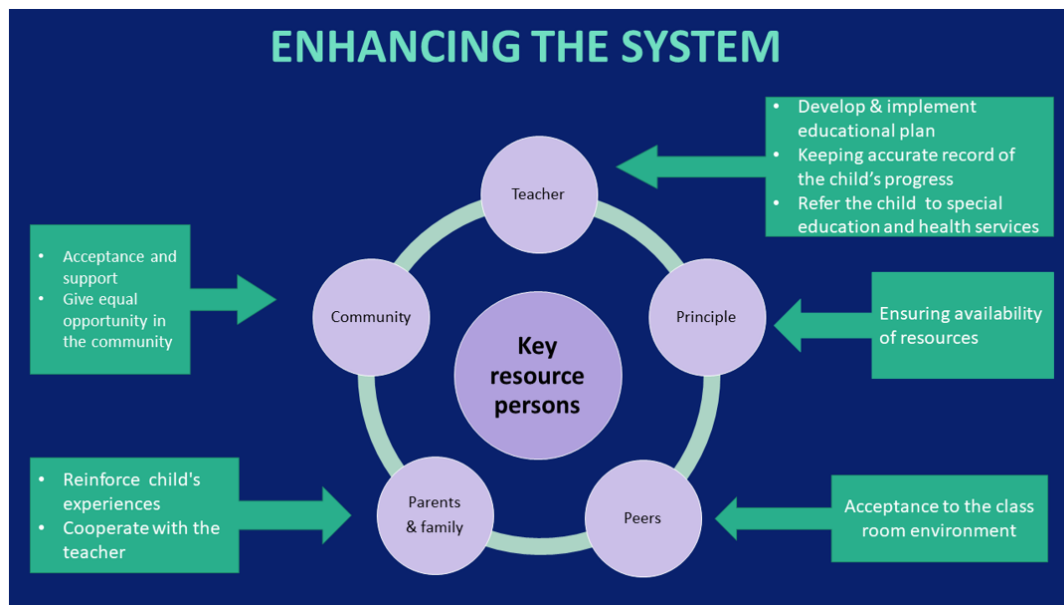


Figure 9.

Psychological and social aspects of childhood blindness

A child with visual impairment invariably requires a large degree of emotional support to help him cope with the disability. Because of stigmas and a lack of awareness of the "outside world", such a child may separate from society, be isolated and withdrawn, anxious, self-conscious, passive and dependent, inexperienced, lack motivation and have predominantly negative attitudes towards blindness. Due to the psychological implications of having visual impairment, a child may become frustrated, and be unable to express himself in a healthy and productive manner. This may lead to behavioral concerns, and "acting out", as a way of coping. It is important to keep this in mind, when dealing with an uncooperative visually impaired student or young patient. When considering the social aspect, there is a great deal of evidence to show that the course of social development is different in visually impaired children when compared to sighted peers. Sight impaired children grow up with confidence only if others around them accept their disability.

To overcome the psycho-social challenges faced by visually impaired children it has been suggested that early intervention is necessary. It is important to structure and guide the child's activities in a manner that allows him to gain experience in a safe environment thereby learning to avoid secondary handicaps. The building of positive attitudes among teachers, peers and family is also extremely important. In this aspect parental counselling is vital. Some parents may not have even realized that their child is sight impaired and may go into a state of extreme grief when they are ultimately faced with the truth. The extent of the child's disability could trigger grief, depression and frustration among the closest family members finally leading to rejection and indifference.

Sight impaired children need help to build their self-esteem. This can only be achieved by positive reinforcement in a manner that makes them believe, that they are not disabled but only differently abled and that they too can achieve almost everything that a sighted child can achieve. Restructuring and modifying infrastructure facilities available however modest they may be, even in the presence of financial and other limitations is also very important in enabling them to overcome the challenges faced in their day to day lives (Figure 10).

On a positive note, I would like to relate to you the inspiring story of a young Sri Lankan boy who was born blind and not blessed with a privileged background at birth. After having achieved very high marks in the grade five scholarship exam he went on to obtain nine distinctions at the G.C.E. Ordinary Level examination. This year in 2021, as a young 17 year old he was able to win 2 Million Rupees, at a general knowledge quiz which is the Sri Lankan equivalent of "Who wants to be a Millionaire". He is a person who has adapted very positively to his disability. He is a classic example of how, even with a disability, one can certainly aspire and achieve.

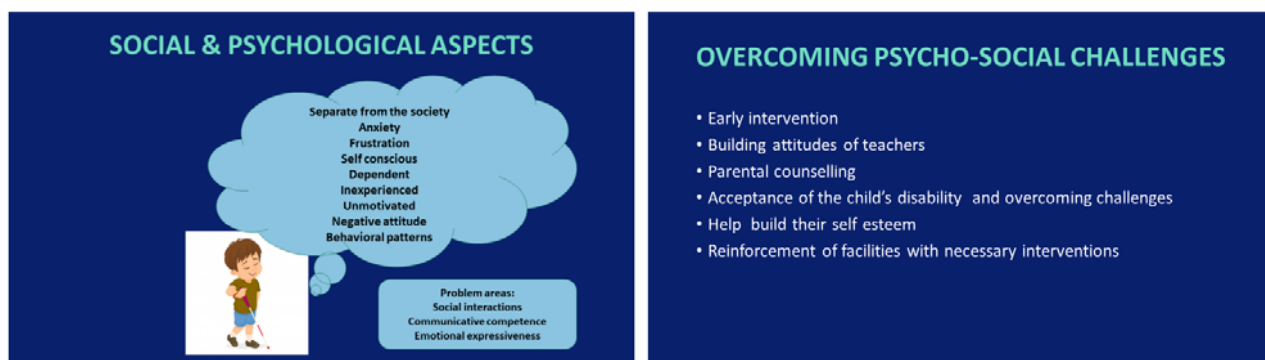


Figure 10.

Blindness in adulthood

Blindness in adulthood is most commonly caused by cataract which is classified as reversible blindness. Irreversible blindness in this cohort is most commonly due to glaucoma, diabetic retinopathy and Age Related Macular Degeneration. Glaucoma represents a group of diseases defined by a characteristic optic neuropathy that is consistent with remodeling of the connective tissue element of the optic nerve head and loss of neural tissue leading to the development of a distinctive pattern of visual dysfunction ultimately leading to blindness. 7.7 million of the population worldwide with moderate or severe vision impairment or blindness is due to glaucoma. Diabetic retinopathy represents microvascular end-organ damage as a result of diabetes. Proliferative diabetic retinopathy without proper treatment can result in tractional retinal detachment and neovascular glaucoma leading to severe visual impairment and blindness. Out of the one billion people with moderate or severe vision impairment or blindness, diabetic retinopathy accounts for 3.9 million (WHO). On the other hand Age Related Macular Degeneration causes primarily a central visual impairment through a combination of non neovascular and neovascular mechanisms ultimately leading to a breakdown of cells in the center of the retina. Prevalence of ARMD in individuals older than 55 years is 1.6% in developed countries.

Creating public awareness among the population at risk, improving and regularizing the available screening programs for common diseases causing irreversible blindness and strengthening the available treatment facilities for these diseases is the way forward.

Impact of loss of sight in adulthood

Vision loss has a significant impact on the life of those who experience it as well as on their families and society. The gradual deterioration of existing eyesight or sudden complete loss of sight can feel frightening and overwhelming. It often leaves those affected wondering about their ability to maintain their independence and mobility together with inadequacies about their ability to cope with life. They also frequently worry about retaining employment, paying for medical care and providing for themselves and their families.

Blindness also magnifies psychosocial problems. Loss of independence affects people's basic ability to care for themselves. Lack of vision directly affects instrumental activities of daily living such as shopping, financial management, medication management and driving. Studies have shown that blindness has a greater impact on instrumental activities of daily living rather than on the basic activities of daily living. It is also known that problems in orientation and mobility co-exist with blindness. Vision impairment has been shown to be associated with an increased risk of fractures in multiple studies.

Psychological problems in the blind are many. Blind people often suffer from various psychological problems because of their disability and their narrowed social environment. Identified problems include anger, rage, social withdrawal, lack of self-confidence and low self-esteem. Multiple studies have concluded that cognitive impairment too is more prevalent and progresses more rapidly in older adults with vision impairment than in those without. People with age-related macular degeneration have higher rates of cognitive impairment, lower scores on cognitive tests, and a higher risk of incident dementia than their sighted counterparts. In conflict situations sudden blindness resulting in post-traumatic stress disorder is well documented. Blind persons often avoid social contact and prefer self-isolation either due to the prejudices or overly sympathetic attitude of sighted people. As Hellen Keller once said "it is not the blindness but the attitude of the seeing to the blind that is the hardest to bear" (Figure 11).

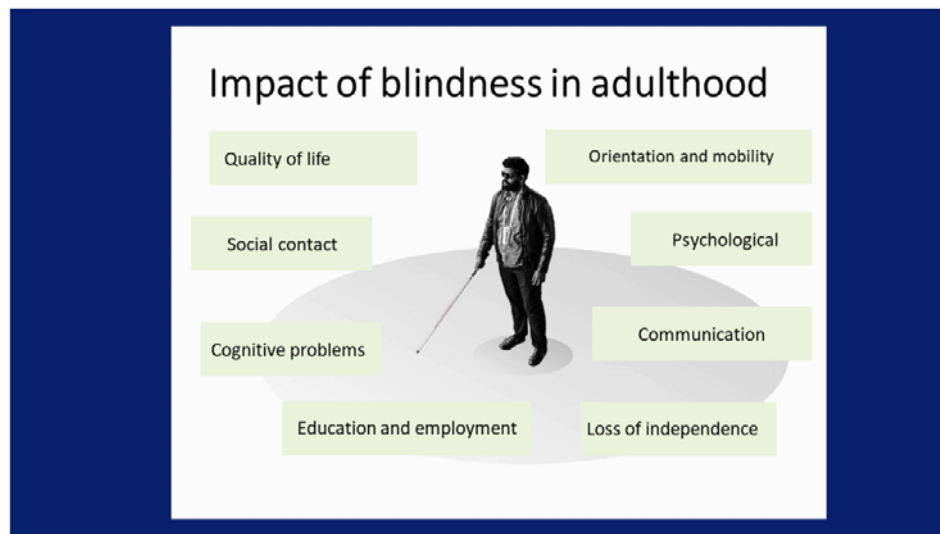


Figure 11.

Adapting to visual impairment

Visually impaired persons are known to adopt a variety of strategies to cope with their loss. These include positive and negative adaptation strategies. Positive adaptation strategies include; acceptance of the disability, trusting in religion together with family and society, positive avoidance of negative feelings regarding the disability, showing independence, minimization which involves viewing the disability in relative terms and thinking other people are worse off than oneself and controlling and compensating for the loss of function through technical aids. Sadly however, negative adaptation strategies are also manifest in blind people. These include denying the disability, resenting or feeling bitter about becoming blind, a sense of shame about being inferior to others, isolating oneself from society and feelings of helplessness and self-pity. Positive adaptation strategies are a coping mechanism (Figure 12).

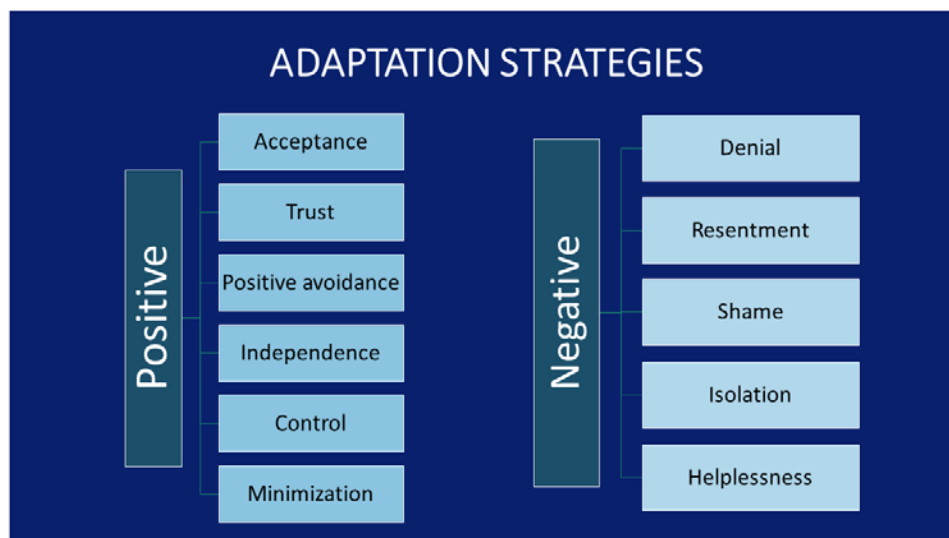


Figure 12.

Rehabilitation of the visually impaired

Rehabilitation is defined as the combined and coordinated use of medical, social, educational and vocational means available to train and retain an individual at the highest possible level of functional ability. Professionals in allied fields, members of society and the state at large are jointly responsible in the rehabilitation of the visually

impaired. In the rehabilitation process, specific attention should be paid to the areas of medical rehabilitation, training and psycho-social rehabilitation and vocational rehabilitation and employment.

Medical rehabilitation should specifically deal with early identification and medical or surgical management of progressive diseases in a timely manner. In the case of individuals who retain some residual vision, Low Vision Aids form an important part of medical rehabilitation enabling them to benefit from their residual vision (Figure 13).

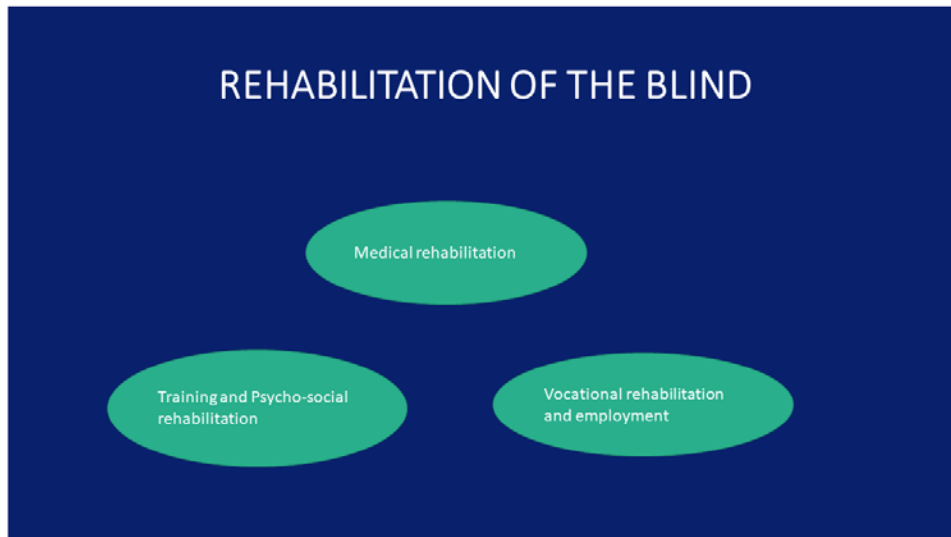


Figure 13.

Training and Psychosocial Rehabilitation is another important aspect in the lives of the visually impaired. This encompasses three areas namely mobility training, training in daily living skills and social support. All nations irrespective of their income status strive to support the blind (Figure 14). However middle and low income countries frequently struggle to prioritize the blind over other socially vulnerable groups. The annual global cost in potential loss of productivity due to blindness and visual impairment has been estimated at approximately US Dollars 410 billion. Worldwide data showed that more than 90% of all blind people lived in developing countries. There is a relative reduction of employment opportunities for people with vision impairment. Blindness indeed is a costly problem (Figure 15).



Figure 14.

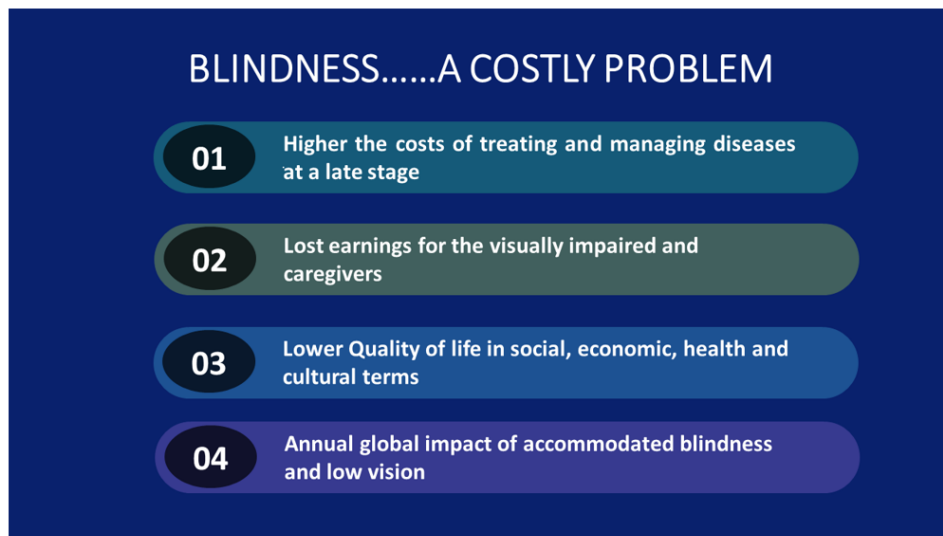


Figure 15.

Intervening and facing the challenges

Currently, screening programs to detect preventable and progressive causes of blindness, such as glaucoma and diabetic retinopathy are being carried out throughout the world. Health education also plays an extremely important part. Health education can be addressed through three avenues the individual approach, the group approach and the mass approach.

Research and development of new technology that is being done globally is also helping humanity to face the challenges of blindness. Now the era of digital health and artificial intelligence (AI) in ophthalmology is already upon us. The digital era has provided new tools that improve the efficiency and availability of existing eye care services. Screening is being carried out through digital health and telemedicine. In telemedicine, electronically transmitted health care data i.e. images, text, or other digital data is forwarded to an ophthalmologist for review enabling a more efficient service. Such advancements will particularly help those living in rural and remote areas of many countries including Sri Lanka (Figure 16).

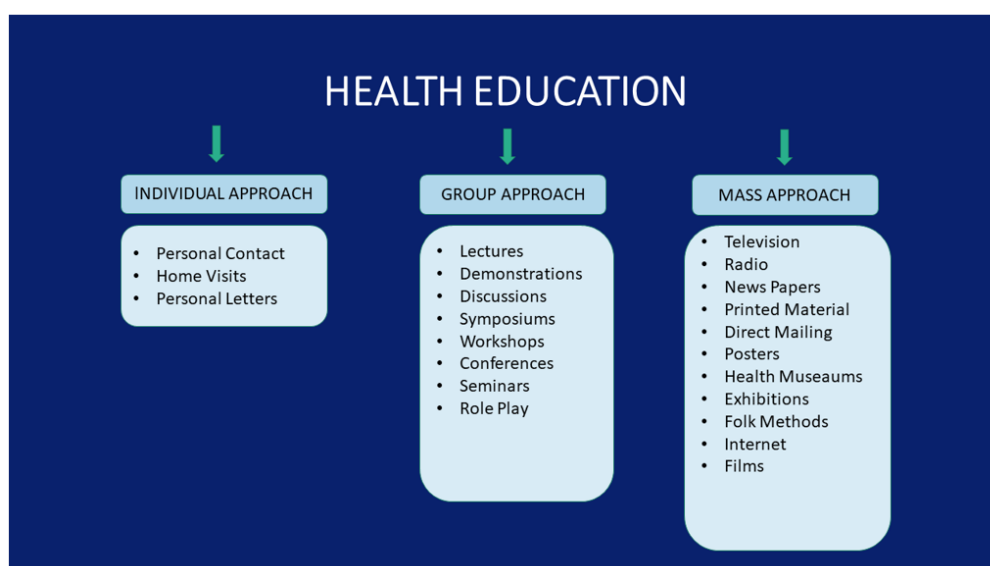


Figure 16.

Artificial Intelligence based systems have the same status as deep-learning computers. These computers are fed with many pictures of the eye, and they can identify the differences between normal and abnormal images within seconds. This information enables the ophthalmologist to intervene early in the disease. As a result of the rapid pace of technological development we expect to witness a global expansion in eye care in the next few years. We only hope that Sri Lankans too can reap the fruits of revolutionary technology without delay.

Restoring sight to the blind

Giving sight to the blind sounds like a magical fairy tale. However, with the advancement in technology, scientists believe it to be a reality. Modern technological integration and medical breakthroughs achieved in the last few decades have enriched ophthalmology and greatly served people faced with a variety of visual problems. Interestingly, these changes have been brought about by the dedicated work of a multitude of people in many diverse disciplines.

In this exciting era, I would like to turn the spotlight on the new hopes in the horizon for visually impaired people. I would like to highlight gene therapy, stem cell therapy and microchip technology as some of the most promising developments. These are overlapping areas of bio medical research with similar therapeutic goals. Both gene therapy and stem cell therapy are being used for the treatment of inherited and acquired diseases.

Gene therapy and genetic engineering are two closely related technologies that involve altering the genetic material. Ocular gene therapy is an emerging technology in the management of inherited and acquired retinal conditions. The term gene therapy broadly encompasses gene replacement strategies designed to replace nonfunctional genes with normal copies in inherited retinal diseases, bio factory approaches to generate soluble proteins, such as anti-VEGF biologic agents for age related macular regeneration and emerging gene editing tools to modify gene expression at the DNA level. The mainstay of these therapies involve intraocular delivery of viral vectors that can carry the therapeutic gene into the nuclei of target cells. This is currently applied in an incurable genetic disease that causes blindness in men – Choroideremia. The injection involves introducing a harmless virus into the retina (Figure 17).

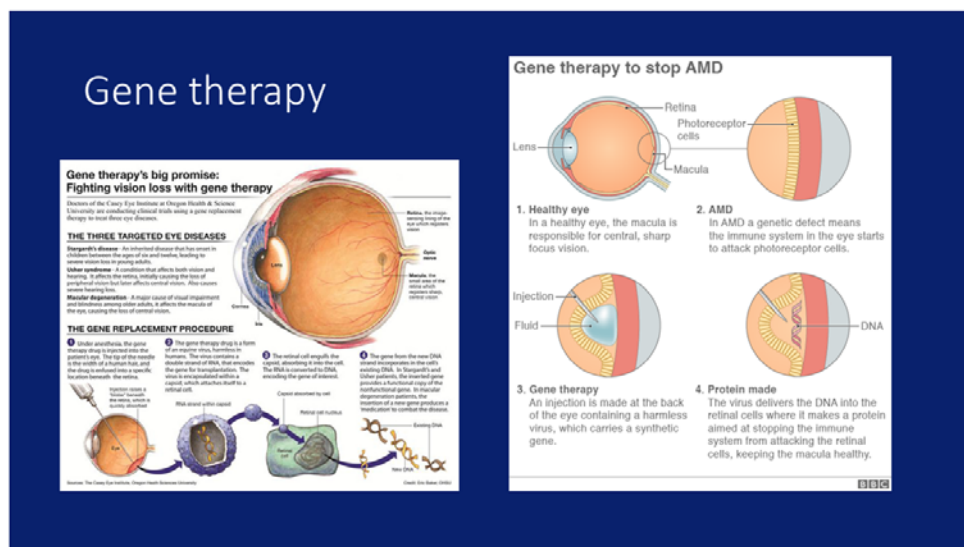


Figure 17.

Stem cell therapy is a form of regenerative medicine, designed to repair damaged cells within the body, by reducing inflammation and modulating the immune system. This makes stem cell therapy a viable treatment option for many medical conditions. The transplantation of retinal pigment epithelial cells, is a popular application of stem cell therapy in the eye. In this process embryonic stem cells are cultured in the lab and converted into mature retinal pigment epithelial cells. In the disease Retinitis Pigmentosa, healthy retinal pigment epithelial cells are injected into the retina. These healthy cells support the non-functioning rods and cones enabling some improvement of vision (Figure 18).

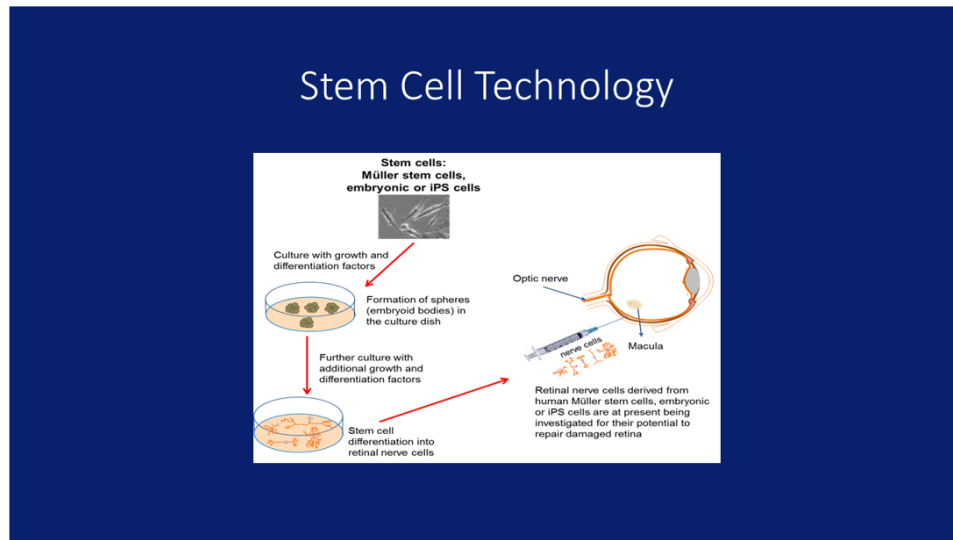


Figure 18.

Microchip technology and signal processing are used to stimulate the natural process of vision. Retinal implants are tiny microchips which are implanted into the retina. These implants have been developed to act as a replacement for lost retinal cells by detecting light and then stimulating neurons. Stimulated neurons will then send signals to the visual cortex. The ARGUS 11 implant (Bionic Eye) that is currently commercially available does not receive light directly but relays signals from spectacle mounted cameras. The implant stimulates the optic nerve and transmits signals to the brain (Figure 19).

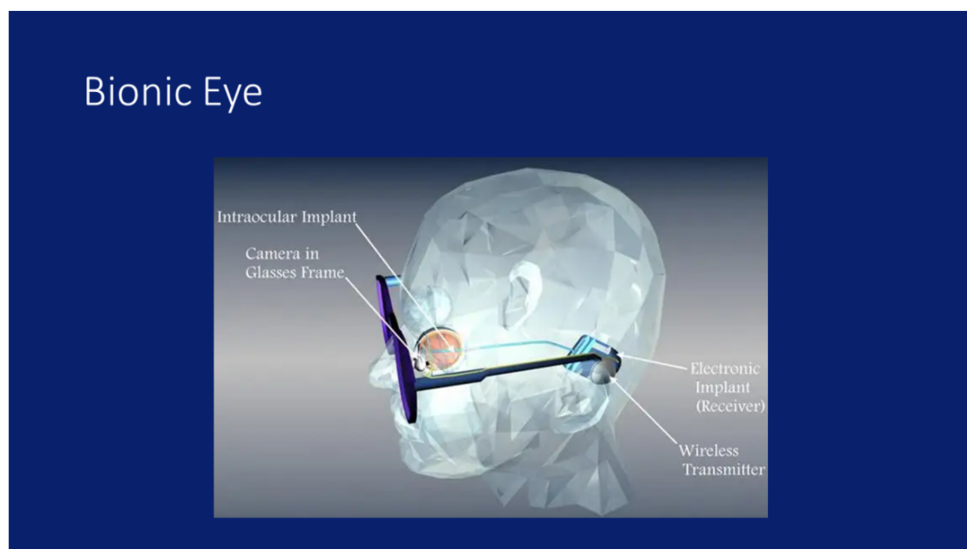


Figure 19.

As Ophthalmologists we cannot consider blindness as an end point and conclude our relationship with the patient stating that no further treatment is possible. We need to ponder if our services can be made available beyond the point of being unable to restore vision. Are we so engrossed in treating the seeing that we are ignoring the non-seeing? With rapidly advancing technology, the future of a visually impaired person is not as bleak as it was before. The time has come for us to unite to give visually impaired persons a better world to live in. We must always believe that there will be a light at the end of the dark tunnel.

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