



GENDER AND BLINDNESS

ADDRESSING INEQUITY

A REPORT BY SEVA CANADA





This report produced in association with:

The British Columbia Centre for Epidemiological and International Ophthalmology (BCEIO), Vancouver, Canada and The Kilimanjaro Centre for Community Ophthalmology, Moshi, Tanzania.

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GENDER & BLINDNESS: ADDRESSING INEQUITY

INTRODUCTION

Seva Canada and its partners' research clearly reveals that, in order to achieve our Vision 2020 goals ¹, eye care programs must develop strategies which help us reach the most vulnerable populations – particularly women and girls. We encourage our program partners to disaggregate data by sex, determine gender-specific barriers to increased uptake of services, and study strategies to increase utilization by women and girls. Seva looks forward to collaborating with all international eye care providers to eliminate all forms of inequities in eye care.



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¹ Vision 2020 is the global initiative for the elimination of avoidable blindness, a joint programme of the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB).





IN 2001, TWO-THIRDS OF ALL PEOPLE WHO WERE BLIND were women, primarily because they were less likely to receive services than men. Between girls and boys, this disparity was even more pronounced. Today, thanks to initiatives like Seva's, the service disparity has decreased from 66% to 56% for women, but it remains the same for girls.

The barriers which prevent women and girls from receiving surgery vary locally but include:

- Lack of financial decision-making capacity
- Inability to travel to health care facilities
- Differences in the perceived value of surgery
- Lack of awareness of information and resources
- Fear of a poor outcome

Seva Canada has taken a leadership role in the gender and blindness global initiative. All Seva-supported projects work towards achieving gender equity by focusing on overcoming cultural and economic barriers. Awareness of the problem has not been enough and much work remains to be done. To achieve the goals of Vision 2020, we need organisations to prioritise the issue of gender inequity, and to encourage both political and social action.

THE CASE FOR EQUITY



A meta-analysis in 2001 found that approximately two out of every three people who were blind in the world were women, most of whom were over 50 years of age, and 90% of whom lived in poverty ^[1]. Furthermore, researchers found that this sex ratio held true for most population-based, age-adjusted, blindness prevalence surveys in Asia, Africa, and even 'industrialized' settings. This sex ratio also held true for virtually all of the preventable and treatable blinding conditions, including cataract, glaucoma, and trachoma.

Cataract: Cataract is the progressive clouding of the lens of the eye that leads slowly to blindness in men and women equally.

Glaucoma: Glaucoma is a group of eye diseases which lead to progressive degeneration of the optic nerve. This in turn can lead to loss of nerve tissue that results in gradual irreversible vision loss and potential blindness if not detected and treated early. Glaucoma is the leading cause of irreversible blindness in the world.

Trachoma & Trichiasis: Trachoma is a chronic inflammatory eye disease. Trachoma is due to an infection with the bacterium *Chlamydia trachomatis* and is the most common infectious cause of preventable blindness worldwide. Over time, repeated infections result in the development of scar tissue on the inside of the eyelid (the conjunctiva), which pulls the eyelashes toward the cornea. This condition is known as trichiasis. When the eyelashes touch the cornea they cause incredible discomfort and damage, which can lead to blindness.



In no instances did biological differences explain the increased prevalence of vision loss among women. Instead, women of all ages (including children) were more frequently exposed to causative factors such as infectious diseases and malnutrition, but utilised eye care services less frequently than men. Based on these findings, in 2001, the British Columbia Centre for Epidemiological and International Ophthalmology (BCEIO) prepared a World Health Organization (WHO) Fact Sheet for the WHO Gender and Women's Health Unit ^[2].

The first International Gender and Blindness meeting was held in Moshi, Tanzania in 2002, co-hosted by Seva Canada, the Kilimanjaro Centre for Community Ophthalmology (KCCO) and the BCEIO and funded by Seva Canada and various Canadian government agencies. Policy, program and research recommendations were produced at the meeting. Many of these were realised over the next decade.

In 2003, the Canadian Global Health Research Initiative ^{[3][4]} provided pilot funding to initiate an international collaboration among epidemiologists, anthropologists and ophthalmologists from Nepal, India, Tanzania and Egypt, known as the Gender and Blindness Initiative.

As a result, gender inequity has been reduced in these eye care programs through public health initiatives and gender-sensitive, community-based service development.

The collaborative approach augmented individual countries' ability to design and conduct applied anthropologic and epidemiologic research. This 'South-South' collaboration, which leads to more effective program sharing and learning, greatly exceeds the far more expensive and less efficient 'North-South' collaboration with Canadian partners.

The primary finding from this Gender and Blindness Initiative is that utilization of eye care services is strongly associated with the socioeconomic status of women, as well as female literacy (as a surrogate for educational attainment)^[5]. Women who have their own source of income generally have greater ability to make financial decisions within the family. Female literacy remains the strongest independent predictor of health service utilization by women across all socioeconomic levels ^[6]. Indeed, examples from Southern India show that an indirect investment in female education improves all aspects of public health ^[7].

The Global Health Research Initiative funds for gender and blindness were followed by sustained local program funding in each of the original members ^[8] as well as new members beyond the four institutions mentioned above ^{[9][10][11]}. The Gender and Blindness Initiative became more comprehensive by explicitly including issues related to trachoma ^{[12][13]} and children ^{[14][15]}. Interest continues from non-government organizations such as Seva ^[16] and within allied organizations such as the Boston-based Women's Eye Health Task Force ^[17].

In 2009 the International Agency for the Prevention of Blindness selected gender and blindness as the theme for World Sight Day and many members of the Gender and Blindness Initiative were active in compiling and producing documents for advocacy at a global scale ^[18].

The Gender and Blindness Initiative attracted new funding to expand the network in Asia and Africa. A 2010 follow-up meeting at the KCCO brought together researchers, Seva Canada and World Health Organization staff and eye programs from Nepal, India, Tibet, Egypt, Kenya, Tanzania, Malawi, South Africa, Congo Republic, Guatemala, UK, USA, and Canada. The meeting reviewed the initiatives since 2002 ^{[19][20][21][22]} while individual researchers discussed their work and implications of their findings.

2017 UPDATE

Gender differences in the prevalence of blindness and visual impairment persist in all regions of the world, and among all age groups ^[23]. Within the most recent global estimate of 36 million people who are blind (<3/60 visual acuity), 20 million (56%) are women ^[24].

Cataract remains the most common treatable cause of avoidable visual impairment worldwide. Uncorrected refractive error, macular degeneration and, in Africa, trachoma, are the next most significant contributors ^[23]. Women experience higher risks of blindness than men from cataract, macular degeneration and trachoma ^[23]. Two reviews of studies of cataract surgical coverage, a measure of utilization of cataract surgical services, revealed that, in most settings women continue to have lower use of cataract surgical services compared to men ^[25] ^[26].

In Sub-Saharan Africa, East Asia and the Pacific, and South Asia, girls are less likely than boys to have surgery for bilateral cataracts, a condition that shows no gender predilection in high-income countries ^[27].

INTERVENTIONS TO REDUCE GENDER INEQUITY

Recognizing that unequal access to eye care services continues to be the primary cause of gender inequities in eye care, Seva Canada and its program partners shifted attention to creating, documenting, and promoting interventions that reduce gender inequity.

REVIEW OF EXISTING EVIDENCE

To understand the current status of evidence regarding interventions to reduce gender inequity, a team undertook a systematic review of the published and unpublished literature ^[28]. There is limited literature available: only 15 studies of interventions to improve access to eye care services were found. ²

The existing publications were considered inadequate scientifically to support specific interventions to reduce gender inequity. Therefore, while the evidence presented below is promising, additional and more precise research is needed in order to reach reliable conclusions regarding the impact of interventions. In addition, most interventions have more than one component, and evaluation studies to date have not been designed to estimate the effect of each component separately.



² There were 4 cluster randomized controlled trials and 11 published observational studies; the studies evaluated interventions for general pediatric eye health (3 studies), age-related cataract (5 studies), childhood cataract (3 studies), and trachoma (4 studies).

WHO IS BLIND?



36 MILLION people worldwide are blind



20 MILLION women are blind

Women are 1.3 times more likely to be blind than men



1.4 MILLION children are blind

2 out of 3 children who are blind are girls



WHERE DO THEY LIVE?

89% live in low and middle-income countries

WHAT ARE THE LEADING CAUSES OF BLINDNESS FOR WOMEN AND GIRLS?

- Cataract
- Retinal Disease
- Trachoma

WHY ARE MORE WOMEN AND GIRLS BLIND THAN MEN AND BOYS?



Lack of financial decision-making capacity



Inability to travel to health care facilities



Differences in the perceived value of female individual



Lack of awareness of information and resources



Fear of a poor outcome

Girls face an additional barrier of being a child, too young to advocate for themselves.



80% OF BLINDESS IS AVOIDABLE BY PREVENTION OR TREATMENT.

4 out of 5 people who are blind don't need to be.

HOW SEVA HELPS



Bridging strategies to connect women and girls to the care that they need



Surgery to treat blindness



Glasses to correct refractive error



Medicine to prevent blindness

SOLUTION

All eye care programs need gender-integrated health interventions to reach **women and girls**. When women and girls are given the power of sight and are able to lead healthy, productive lives, **entire communities** have a chance at a better future.



GENERAL EYE HEALTH

An unpublished study in Same District of Tanzania evaluated a multicomponent intervention. This intervention involved training members of microfinance groups to educate individuals in their community about available eye care services, and to assist those in need to overcome barriers in attending outreach clinics. Women, women's groups and their networks are seen as the key social actors and mechanisms for influencing community health-seeking behavior. As women and women's groups are taking on and controlling economic activities in communities, their decision-making authority grows within families. Microfinance initiatives, while variable in size and function, usually include a dominant role for local women in defining the structure and function of the organisations. The intervention did not change clinic attendance rates but improved gender equity in the acceptance of cataract surgery ^[29].



AGE-RELATED CATARACT

Several interventions sought to improve access to care for women for age-related cataract. There have been a series of population-based surveys in the Lumbini Zone of Nepal. The studies showed the efficacy of a community ophthalmology program that began in the year 2000 using female community health volunteers who improved women's awareness of, and access to, existing surgical services. In the 2006 blindness (<6/60) survey the prevalence had switched to favouring women over men, when compared to a decade earlier which favoured men over women ^{[30][31]}. The reversal is almost certainly due to increased cataract surgical coverage in women (70.8%) versus men (61.7%) in the 2006 estimate compared with the 1995 estimate (women 40.6%, men 44.2%).

Outreach screenings in rural villages in China identified more women in need of cataract surgery than standard clinic referrals ^[32]. A Tanzanian study reported on factors associated with improved access to care for women ^[33]. They found that community-based services had a significantly higher proportion of women versus men receiving care compared to hospital outpatient services. This provides some evidence that outreach activities decrease gender inequity compared to patients who come to the hospital directly.



TRACHOMA AND TRICHIASIS

Three studies report on interventions aimed at improving access to care for women for trichiasis surgery. Trichiasis is the sight-threatening consequence of scarring of the eyelids due to trachoma, the most common infectious cause of blindness worldwide. Multiple infections from childhood cause the eyelashes to eventually turn in and scar the cornea which can lead to blindness.

A study in Egypt undertook community mobilization and healthcare provider capacity-building to improve access to trichiasis surgery. As a result, gender inequity in the prevalence of trachomatous trichiasis was reduced ^[34]. A systematic review of population prevalence studies suggests that the WHO-recommended SAFE strategy (Surgery, Antibiotics, Facial hygiene, and Environmental improvements) for trachoma control does not reduce the inequitable burden of trachoma experienced by women ^{[13][35]}. However, a study of gender equity in Tanzania and Vietnam found that the female to male rate of surgery was the same or even higher than the female to male rate of trichiasis in the population ^[36]. The authors concluded that there was gender equity in the provision of trichiasis surgery in both countries.



Four studies report on interventions aimed at improving gender-specific access to care for children. In Tanzania and Nepal, specific interventions led to a reduction in gender inequity in post-operative follow-up for childhood cataract [37][38][39]. In Nigeria, surgical fee reduction alone did not change gender equity in utilization of surgery for adult and pediatric cataract demonstrating the need for active community-based interventions [40].

A recent study of five tertiary-level (teaching and referral) facilities in Africa and Asia found consistent and persistent sex disparity between boys and girls, even in facilities that had adult programs that had reduced adult gender inequity [41]. These institutions incorrectly assumed that the successful gender equity interventions used for women would be sufficient to result in similar success for girls. In fact, they were largely unaware of the gender inequity in their pediatric program, particularly in terms of case finding. Interviews with community-based case finders almost all strongly stated that the key issue is not finding girls in need of treatment, but getting the families to comply with the recommended care. Once children were within the eye care system, boys and girls received similar procedures and follow-up care.

SUMMARY OF FINDINGS AND EXPERIENCE

Based on Seva Canada's experience and research findings, the following conditions are necessary to achieve gender equity in eye care utilization in a community:

- 1 A recognition of the issue of gender and vision loss.
- 2 Strong eye care program leadership committed to equitable provision of eye care services, including dedicated staff time and program funding to reach target populations.
- 3 Sex-specific data gathering and reporting, at all levels.
- 4 Ongoing active engagement with female community leaders and organisations.
- 5 Promotion of community and household support for positive eye health-seeking behavior.
- 6 Counselling of the entire extended family involved in financial decision-making.
- 7 Monitoring and evaluation of sex-specific case finding and utilization strategies.
- 8 Feedback to community-based case finders regarding feasible solutions.

In addition, requirements to achieve gender equity of service utilization for children include:

- 1 Community case finders that are aware of low acceptance of service, particularly among girls.
- 2 An eye care utilization/acceptance program to follow up the community-based identification program.
- 3 A dynamic record keeping system to promptly inform case finders of referred children's progress.
- 4 Specific programs to connect children within isolated ethnic groups to eye care services.



By recognizing that gender equity depends on complex socioeconomic factors and often rigid cultural norms, eye care programs have not directly challenged gender barriers or the inequalities that shape them. Instead, the program managers employed strategies that accommodated these inequalities and barriers by ‘working around them’, thereby increasing access to and use of health information and services and improving health outcomes. The approach reflects the major findings from a systematic review of interventions to improve gender equity.

“The results of interventions that worked around gender barriers to health services were positive, but not as compelling as those for interventions that sought to transform inequitable gender norms. In some sociocultural contexts, these accommodating strategies may be the most appropriate, particularly as the first step in integrating gender into health programming” ^[42]
{Public Health Foundation of India 2014}

Integrating a gender perspective into health interventions means explicitly considering the ways that gender can influence access to care. “Gender-integrated” interventions actively attempt to improve gender equity in health through elements of their design, implementation, monitoring and evaluation ^[43]. Gender-integrated health interventions can be further categorized as either “gender accommodating” or “gender transformative” ^[43]. Gender accommodating strategies aim to improve gender equity in health by working around the barriers to health care access imposed by entrenched gender norms and power relationships. In contrast, gender transformative strategies directly challenge harmful gender norms and foster more equitable relationships between women and men with the aim of improving health for all.

Among the interventions reviewed, the one in Lumbini Zone, Nepal, is predominantly gender accommodating ^[50]. Recognizing that women are typically disadvantaged in their access to health education and services, the intervention used female community health volunteers to bring eye care knowledge to women in their communities and assist them in accessing services. Although not explicitly gender-integrated, the interventions that made use of door-to-door health education, ^[34] outreach screening, ^[32] and assistance with transport and accommodation ^{[34][39]} could also be considered gender accommodating. In contrast, the intervention in Same District, Tanzania, is an example of a predominantly gender transformative intervention because it attempted to modify some of the economic and decision-making dynamics at the household and community level, which can act to prevent women from accessing health services ^[29]. All of these interventions showed promise for improving gender equity, though further research is needed to confirm their effectiveness.

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