

Civil Society and Blindness From Glaucoma in Sub-Saharan Africa

Achieving cost-effective, sustainable care in this region.

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The concept of a civil society as defined by the authors is a crucial component of tackling glaucoma in many less-developed areas. The primary goal is the creation of a self-sustaining system. For those working as individuals, the problems are formidable, and industry often considers these areas unprofitable to support.

Govindappa Venkataswamy, MD, the founder of Aravind Eye Care System in India, would have us remember that health care and eye care initiatives do not occur in a vacuum. Rather, they must be tailored to the needs and potential capabilities of a specific community. The goal is to improve the well-being and eye care of the community, not just that of a group of individuals. Quality and capacity building are crucial to this endeavor.

Partnerships with organizations such as Lions Aravind Institute of Community Ophthalmology, nongovernmental organizations, and interested individuals are all important. Steps include not only examinations and surgery but also recruitment, marketing, outcomes analysis, fundraising, instrument repair, and managerial skills. Diverse partnerships with interested parties will be the key to expanding access to high-quality eye care.

—Alan L. Robin, MD, section editor

Glaucoma is a leading cause of blindness globally, with a disproportionately high impact in Sub-Saharan Africa (SSA), where the estimated prevalence is at least 4% among individuals 40 years of age and older.¹ Despite this high burden of disease—which often has devastating psychological, social, and economic consequences for those affected and

their communities—glaucoma was not included among the priority diseases in the first draft of the global Vision 2020 The Right to Sight initiative.^{2,3} The reason was the lack of clear-cut public health strategies for controlling glaucoma at the time, unlike with the other major blinding eye diseases. There is, nevertheless, an urgent need for effective and sustainable glaucoma care in SSA. Goals include enhancing community-level awareness of disease, overcoming various barriers to access, providing essential medication and equipment for diagnosis and management, enhancing patients' adherence to treatment, training ophthalmic health care personnel at various levels, and integrating a strong international standard of ophthalmic care into the broader health care infrastructure. Also critical is the adoption of an evidence-based approach to best practices in order to inform and sustain programs and policies over time.⁴ The public sector has made some strides in these areas, but much remains to be done.

His Highness the Aga Khan stated, "In an era of rising expectations and unmet needs, both in the developed, but much more in the developing world, civil society institutions play an essential role in the provision of social services, the protection of the marginalized, and the delivery of development programmes."⁵ Our deeply held conviction is that civil society can play a key role in strengthening institutional capacity for cost-effective and sustainable glaucoma care within SSA.⁶

CHALLENGES IN GLAUCOMA CARE IN SSA

Eye care in Africa continues to pose enormous challenges, and blindness does not occur in a social

LIONS ARAVIND INSTITUTE OF COMMUNITY OPHTHALMOLOGY

The Lions Aravind Institute of Community Ophthalmology (LAICO; laico.org) was established in 1992 as a consultative and capacity-building branch of the Aravind Eye Care System in India. LAICO emphasizes the importance of an “enabling environment” in the success and sustainability of any eye care hospital. Beyond the clinical facets of ophthalmology, LAICO seeks to address the internal and external factors relating to effective program design, governance, and efficiency management.

Phases in consultancy process

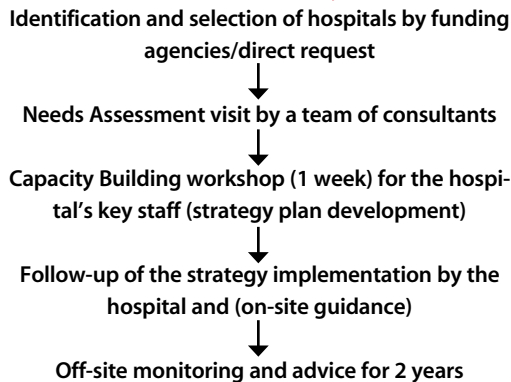


Figure. The phases of the LAICO consultancy process. Reproduced with permission from http://www.aravind.org/downloads/LAICO_Consultancy_Brochure.pdf.

LAICO teams conduct on-site assessments of needs to establish a strategic framework for capacity building specific to each hospital (Figure). Through an intensive series of workshops, the hospital team is encouraged to develop a shared vision and formulate strategies by which to make that vision a reality. A detailed plan of action with a set time frame for completion is developed. Follow-up visits are then conducted by LAICO to ensure the effective translation of plans into action.

vacuum. Rather, it reflects the broader educational, socioeconomic, and developmental obstacles faced by communities throughout SSA. A key issue is the well-documented shortage of clinically trained eye health professionals at all levels. Resnikoff and colleagues estimated the prevalence of ophthalmologists to be only 1.0 to 3.1 per 1 million population in SSA.⁷ In addition to inadequate human resources and a lack of effective leadership, there is a paucity of strong institutional

infrastructure and strategic management as well as a knowledge gap arising from limited education and research programs, all of which converge to perpetuate the inequities associated with eye care in SSA.⁶⁻⁸ We believe that it is at this systems level that civil society can have a profound impact on glaucoma care in SSA.

THE ROLE OF CIVIL SOCIETY IN GLAUCOMA CARE

The World Health Organization defines *civil society* as “an aggregate of non-governmental and not-for-profit institutions, powered by private voluntary energies and committed to the public good.”⁹ In effect, they represent the third sector of society, distinct from and yet simultaneously interdependent on both government and the private sector for social and economic change. Civil societies have increasingly become important drivers of the delivery of social services and the advancement of health-related quality of life; their actions complement those of governments, especially where governmental presence is weak or insufficient.¹⁰

Given this mandate, civil societies can form effective partnerships with local, regional, and international partners, within both the public and private spheres, to foster change in glaucoma care in SSA. Opportunities for collaboration are many: sharing of best practices, twinning of institutions, political and other forms of advocacy, quality improvement in the delivery of health care, training and continuing education of health care personnel (including in the areas of leadership and managerial skills), and support of monitoring and evaluation frameworks as well as of research.¹¹

Also important is building capacity for detecting and managing glaucoma at the primary, secondary, and tertiary levels. This step involves identifying needs and opportunities, developing mutual goals, drawing on mutual strengths, and fostering partnerships designed to ensure quality and equitable access for those otherwise deprived of eye care. An organization experienced in this process is the Lions Aravind Institute of Community Ophthalmology. It provides consultative services to enable the building of institutional capacity and strengthening of health systems throughout the developing world (see *Lions Aravind Institute of Community Ophthalmology*).

Additionally, educational partnerships between academic institutions in SSA and those in developed countries can facilitate the training of eye care professionals. These collaborations can allow bidirectional capacity development and the sharing of best practices. Examples include the Vision 2020 Links Programme, the Aravind Eye Care System’s international training course in glaucoma diagnosis and management, and the interinstitutional collabora-

THE "SANDWICH" MODEL OF EDUCATION

Sheila Marco, MD, from the University of Nairobi, was one of the first graduates of the "sandwich" fellowship at the University of Alberta (Figure).¹ Since returning to Kenya, Dr. Marco has led and streamlined the Glaucoma Service at the University of Nairobi. She has been involved in curricular reform for residency training, the development of guidelines for glaucoma care in Kenya, and raising public awareness of glaucoma, particularly in rural communities. She is also involved in clinical trial research for improved glaucoma surgical care for her patient populations.



Figure. Dr. Marco and her preceptors from the University of Alberta, Edmonton. Pictured from left to right: Dr. Michael Dorey; Dr. Marianne Edwards; Dr. Sheila Marco and her son, Austin; and Dr. Karim Damji.

Dr. Marco is one of a number of graduates from this unique program. She has become a leader in her field and an advocate for the strengthening of institutional and systems capacity in her region. Civil society partners that supported her training include Orbis, the International Council of Ophthalmology, the Eastern Africa College of Ophthalmologists, LV Prasad Eye Institute, and the Royal Alexandra Hospital Foundation (Alberta).

1. Maurier R. Kenyan eye specialist hones skills through 'sandwich fellowship' in ophthalmology. University of Alberta website. <http://www.news.ualberta.ca/newsarticles/2011/07/kenyanophthalmologist>. Published July 15, 2011. Accessed September 9, 2013.

tive "sandwich" model of education.¹²⁻¹⁴ The last promotes subspecialty training that meets international standards and the simultaneous development of institutional capacity to foster an environment that will retain the individual. Emphasis is placed on affecting the quality of care and education locally as well as on continued research and knowledge translation. The success of this program is exemplified by one of its recent graduates, Sheila Marco, MD (see *The "Sandwich" Model of Education*).

CONCLUSION

Given the shifts in demographics, the daunting burden of glaucoma in SSA is likely to grow in the decades ahead. Civil society can be instrumental in meeting the challenge through local and international partnerships to develop institutional capacity, nurture local leaders, and advance the delivery of quality eye care to SSA. As His Highness the Aga Khan noted, "such partnerships will require a profound spirit of reciprocal obligation and mutual accountability—a readiness to share the work, share the costs, share the risks and share the credit."¹⁰ We hope that civil society partners vigorously engage in the development and strengthening of sustainable institutional capacity in order to realize the more equitable delivery of glaucoma care throughout SSA. ■

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