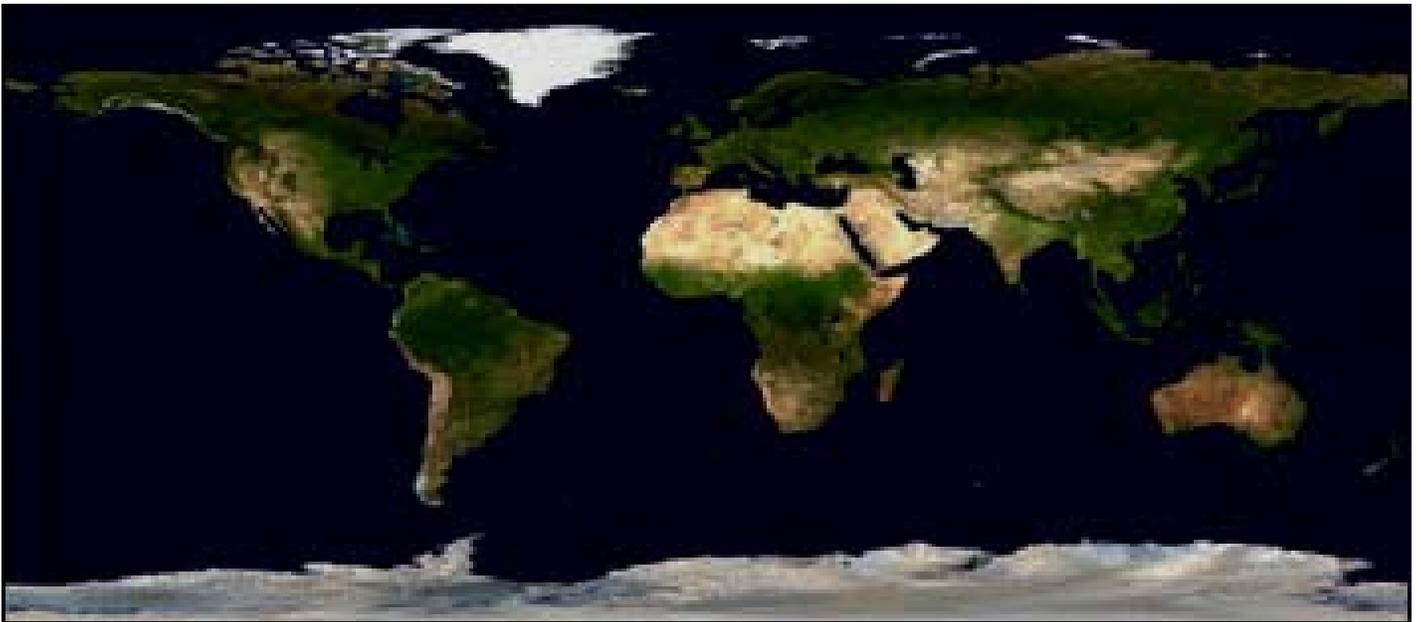


TOWARD A REDUCTION IN THE GLOBAL IMPACT OF LOW VISION



OSLO WORKSHOP

OCTOBER 2004

The Oslo Invitational Workshop was sponsored by



through its Mrs. Cecilia Schupf and Paul J. Schupf Invitational Symposium Series

and by



with additional support from:

Stockholm Institute of Education

and

Oslo University

Published by The International Society for Low-vision Research and Rehabilitation, New York, NY USA

March 2005

Table of Contents

Introduction	1
A Framework for Low Vision Service Delivery	4
A Research Agenda for Low Vision	7
Functional Epidemiology of Low Vision.....	7
Outcome Studies: The Evidence Base for Low Vision Services	8
Research and Development (R&D)	9
A Call to Action	10
Summary and Conclusions	13
References	16
Participants	17

Introduction

Low vision refers to reduced ability to carry out important life activities including obtaining an education, living and traveling independently, being employed, and enjoying and seeing visual images, due to visual impairment that cannot be corrected with medical treatments, ordinary glasses or contact lenses. The World Health Organization (WHO) has recently estimated that as of 2002, there are at least 161 million visually impaired persons worldwide, of which 37 million are blind (Resnikoff *et al.*, 2004). The vast majority are from developing countries. Based on reasonable assumptions (Paragasegaram, 2004; World Health Organization, 1996) an estimated 61 million of the visually impaired population, are likely to benefit from low vision services.

The Oslo Workshop, an assembly of 25 geographically and professionally diverse experts, took place October 17-21, 2004, near Oslo, Norway. This group envisioned a world where all who are permanently visually impaired can realize as much visual function as possible and enjoy the same opportunities and responsibilities as those who are fully sighted. While there are ample economic reasons for society to provide low vision services, such services should be considered a human right to be given independent of economic justification.

The failure to provide appropriate low vision services prevents many individuals from achieving full social inclusion and optimal quality of life, increases costs to society, and deprives society of the human and economic contribution of those individuals. Because the relationship between low vision and blindness has only recently been well understood, low vision has received very little attention by societies worldwide, and in most places has not yet been successfully integrated into the healthcare, education or rehabilitation systems, nor indeed even into public consciousness. This is remarkable as the vast majority of all people identified as visually impaired have low vision.

While there are many possible definitions of low vision services, we define them here, for the purpose of this document, as any service for the purpose of improving the use of available and functional vision, recognizing that these services may include and be delivered by a very broad range of disciplines and social processes throughout the world.

There are several existing international efforts for blindness prevention that seek to eliminate avoidable blindness and reduce or eliminate the effects of partial and complete vision loss, most notably the Vision 2020 Initiative started by the International Agency for the Prevention of Blindness (IAPB), an umbrella organization of eye care professional groups and nongovernmental organizations (NGOs) in partnership with the World Health Organization (WHO), and several other international organizations that have supported the Vision 2020 initiative. These include but are not be limited to the World Blind Union (WBU), the International Council for Education of the Visually Impaired (ICEVI), Christoffel-Blindenmission (CBM), Sight Savers International (SSI), Lighthouse International (LHI), and Helen Keller International (HKI). It is our intention that actions stemming from this document be coordinated with these efforts, and serve as one part of a comprehensive strategy to raise awareness and resources, and advocate for the

development of low vision services in concert with an overall prevention of blindness program. This involves social change, and requires the participation of policy makers, social advocates, and public educators, as well as efforts within the medical, educational, and vision rehabilitation communities.

The Vision 2020 initiative is important, because it is a well-organized international attempt to address the closely related problem of blindness, with its major objective to eliminate preventable blindness by the year 2020. The Oslo Workshop participants felt that an enhanced recognition of the importance of low vision services within the Vision 2020 proposal can significantly reduce the overall impact of visual impairment around the world. Since a substantial proportion of the visually impaired population around the world has irreversible, unpreventable low vision, reducing the global impact of visual impairment entails providing low vision services and addressing the specific needs of the low vision population. This should be a goal that stands alongside, rather than within, the goal of eliminating preventable blindness.

This document outlines:

- a general framework for low vision service delivery that can be used both to describe existing services throughout the world and to propose improvements to service organizations and processes within existing medical, educational, and rehabilitation facilities, and the development of new services where they currently are within reach or do not exist in developed or developing nations.
- an agenda for research in low vision to support national and international advocacy efforts that form the basis of both civil rights and sound economic policies and services that are based on scientific research, development, and evaluation.
- an international Call to Action for government and NGOs and other stakeholders to raise awareness of low vision, increase resources for low vision research and development, education and rehabilitation, and include these into global healthcare, rehabilitation and education initiatives.

We recognize that existing initiatives to diminish blindness and its impact already incorporate components that impact those with low vision. We endorse these efforts, and undertake to coordinate our Call to Action with those of other organizations, such as the Vision 2020 initiative, which seeks to work primarily through the international health system, and the World Blind Union, which seeks to work primarily through national NGOs and consumer organizations.

We endorse a definition, for purposes of characterizing the size of the low vision population, as visual function of a person who, even after treatment and/or standard refractive correction, has, in the better eye, a visual acuity ranging from less than 6/18 (0.3) to light perception, or a visual field whose extent in all

directions around the fovea (i.e., around the physiological center of the visual field) is less than 10 degrees (i.e., a diameter of less than 20 degrees) in the eye with the field of greater central extent, but who uses, or is potentially able to use, vision for the planning and/or execution of a task.

This definition is similar to the “Bangkok” definition proposed in 1992 (World Health Organization, 1992), but is somewhat more concise. Still, it may fail to capture people with low vision who have specific neurological deficits that interfere with visual processing, and some with visual acuity better than 6/18 (0.3) who, due to decreased contrast sensitivity, oculomotor or other deficits, experience significant visual problems.

We note a relatively recent shift of thinking that both the “Bangkok” definition and our definition espouse: the vast majority of people in the world who are considered blind (by some legal definition) in fact have low vision, and are in principle capable of and wish to use their vision for tasks commonly accomplished non-visually by totally blind people; they typically do not use a white cane, and do not require braille or voice to read text, given appropriate aids and education.

We make the following general statements:

1. Access to low vision services is a basic human right at the same level as the right to appropriate healthcare, education, and rehabilitation. Thus low vision care should be available to everyone who can possibly benefit from it.
2. Low vision is distinct from blindness (even though domain-specific definitions may overlap), and the use of functional vision should be encouraged and assisted by appropriate devices and instruction, so as to maximize task performance and quality of life where vision is the more efficient and preferred sensory modality.
3. There is a great need for the general public and those with vision impairment (both those who have low vision and those who are blind), to be educated about the causes and functional effects of low vision. All need to be made aware of the possibility of enhancing visual function through low vision services. This will help to reduce or eliminate the perception of low vision as a stigma, and to make low vision-specific behaviors (e.g., reading at very close distances, eccentric viewing) and the use of devices (e.g., spectacle magnifiers and strong plus lenses) more socially and cosmetically acceptable.
4. Low vision needs to be included in the instructional curricula of all professionals, who are likely to be in contact with individuals with low vision, including but not limited to, all eye care professionals, special and general educators, elder/geriatric care professionals, and those in generic and specific rehabilitative services.

A Framework for Low Vision Service Delivery

The goals of low vision service delivery are multi-faceted, because the impact of low vision affects the lives of individuals in deep and far-reaching ways throughout their lifespan. Low vision often results in emotional distress and depression, unemployment or underemployment, illiteracy and other educational disadvantages, such as lack of inclusion in schools. Low vision can result in loss of independence in personal financial management, mobility and travel, personal care and other activities of daily living, and social interactions. It may isolate individuals and reduce access to practical and cultural information usually obtained through reading, television, computer and internet, and other visual media as well as information that is obtained on a day-to-day basis through the visual sense in those with normal vision. When low vision is congenital, it may place the child at risk for developmental delays. When developed in late adulthood it may increase the individual's risk for other health conditions including mortality.

In some parts of the world (including developed nations), those with low vision are only taught compensatory strategies that do not allow for the use of vision. This approach is not consistent with the Oslo group's efforts to encourage low vision services or the efforts of those who wish to "prevent blindness." Indeed it may needlessly limit the functional visual capacities of the individual with low vision.

We propose that service delivery needs to be coordinated with extensive public education and outreach activities, not only to serve more individuals with low vision, but also to make low vision a more common, visible, and socially accepted condition, as much as physical disabilities have become in recent years.

We endorse the WHO classification and recommendations of how low vision services are to be delivered in primary, secondary and tertiary levels of care, as previously described in a WHO Asia Pacific Regional Low Vision Workshop report (World Health Organization, 2001), and summarized below, and we extend those recommendations to include and emphasize other low vision service providers, especially in the education and rehabilitation systems. It is imperative that low vision services be provided with standard eye care in this scheme, in coordination with schools and rehabilitation systems (where these exist apart from medical care). In some regions with limited resources, this integration may pose a special challenge.

Primary care is community based, and is provided by primary health care workers, primary eye care workers, community-based rehabilitation workers, consumer advocates, and, in the educational system, teachers. Typical activities include raising awareness about low vision, screening, referral and basic rehabilitation.

Secondary care is provided in smaller private and public facilities including regional hospitals, and professionals' offices, and is provided by a range of professionals, usually according to national custom, including optometrists, ophthalmologists, ophthalmic medical assistants, clinical low vision specialists and therapists, orthoptists, and other multi-skilled workers. Secondary care provides diagnosis and treatment, refraction, low

vision assessment, prescription of low vision devices and instruction in the use of devices. In the education system, secondary low vision care would be addressed by special educators and by resource centers that are designed to facilitate inclusion of the student (where possible) into standard classroom activities through the use of devices and instruction. In some locales, where rehabilitation stands apart from standard eye care, low vision services may be delivered through stand alone-rehabilitation centers.

Tertiary care is characterized by multidisciplinary services, and is typically provided in large hospitals where a variety of eye and health care providers are situated and available for referral and consultation, in a comprehensive vision rehabilitation setting with referral and collaboration to and from a medical facility, or in specialist multi-disciplinary centers. In addition to the typical activities of secondary care, it includes prescription of high power and complex low vision devices and may include a much broader spectrum of interventions, including special education, orientation and mobility training, rehabilitation teaching, psychological or social work counseling, and job training. In addition to those of secondary care, personnel may include orientation and mobility specialists, rehabilitation specialists, and/or low vision therapists, teachers, social workers, and researchers. Tertiary care facilities typically include professional training of health, eye care, education, and rehabilitation professionals. Tertiary facilities should include (and benefit greatly from) program evaluation and/or outcomes research.

The above classification is general in nature, and does not reflect all aspects of low vision care or services throughout the world, but serves as examples of well-functioning systems. For example, for an individual to derive maximum benefit from devices and training it may be necessary for one or more of the team members to go to the home, school, or employment setting to provide environmental adaptation and to ensure that the instruction received is appropriate and that the prescribed devices function as intended. Also, with children, it is often necessary at the secondary and tertiary levels of care, to work with individual teachers to facilitate integration of the low vision service into the child's educational setting.

There is great variety in models of low vision care throughout the world, sometimes even within a single country. Not surprisingly, services tend to be at a higher level of care and more available in urban settings, and in countries with greater economic resources and social systems for care and rehabilitation. In developing nations, services are often utilized more by males than females. Even in the developed nations that have extensive low vision services available, however, the low vision population is vastly underserved, relative to those with other disabilities. It is recommended that low vision services be integrated into each level of care, for at least the eye care and educational systems, and where rehabilitation operates apart from the medical system, in the rehabilitation system as well.

Modifications to the built environment and to publicly available information systems are another type of intervention that can provide access for individuals with low vision, and even help raise awareness about low vision. Disability civil rights laws that exist in many countries should be enforced and extended to make environments more

visually accessible to those with low vision. Often, required modifications are extremely simple, such as making sure that signs can be placed at a close viewing distance to be seen with a magnifier, or using high contrast signage with legible typography. In most instances, modifications for low vision are consistent with the principles of universal design, and can therefore be coordinated with the efforts of other disability groups. However, there is a need for human factors research that can make specific recommendations for environmental modifications and improvements in the accessibility of information systems including the internet (see Research section below).

Educational systems are separate from healthcare systems nearly everywhere in the world, and it is important that educators be made aware of the availability of appropriate services in the healthcare system, to maximize the ability of children with low vision to access information visually. Early intervention programs, which foster infant concept development through instruction in visual efficiency and development, benefit from refraction in the interest of providing to the infant the best possible retinal image. Similarly, literacy, a foundation for nearly all education, depends on providing appropriate optical, non-optical and electronic devices for the students, highest contrast, and legible images both near and at a distance. Equally important, however, is the provision of appropriate instruction in the use of such devices, and the familiarity and knowledge of both the educator and the family of the visually-impaired students. It is of course understood, that with severe low vision, tactile or auditory approaches may supplement vision or be preferred for specific tasks.

Thus delivering low vision services involves efforts that reach beyond the health care system, and into the areas of disability rights and of education. Because of the variety of practiced models of service delivery, the greatest challenge is in identifying appropriate key people and organizations within each nation or locale who can lead the low vision effort, advocate for change, and coordinate the efforts of primary, secondary and tertiary health care with those of the school system, and in many cases the rehabilitation system.

A second challenge is in identifying appropriate staff and providing professional preparation for them to deliver low vision care. There will be considerable variety in this across countries. In some countries, for example, ophthalmologists are the appropriate providers of optical devices, whereas in other countries, optometrists, opticians and other professionals would be the most appropriate. Similarly, in different locales rehabilitation teachers, special educators, occupational therapists, low vision therapists, ophthalmic assistants and orthoptists, might each be responsible for providing instruction in the use of prescribed optical and non-optical devices and environmental modifications in the home, classroom, or work environment. What is most important, however, is that low vision be included in all three levels of care, and that all professionals who come in contact with those with low vision be made aware of the existence of resources and ways to make appropriate referrals for services that result in better outcomes for individuals with low vision and the societies in which they live.

A Research Agenda for Low Vision

In Oslo, we identified a substantial body of needed research to support improved models of service delivery worldwide. Much of this research would identify need through epidemiological studies, and support an evidence base for low vision interventions.

For the purposes of this agenda we define low vision research as data acquisition studies, as well as quantitative and qualitative studies that gather and interpret scientifically obtained data for the purpose of improving the use of functional low vision. These may include, but not be limited to, studies of populations, interventions, service delivery, and outcomes of public policies, that address the needs of the low vision population as a group; or they may target a population of people with a specific eye condition, e.g., oculocutaneous albinism, a world wide cause of low vision. Such research would include services delivered in primary, secondary and tertiary settings, but it would also include research within educational and rehabilitative programs, as well as research on the unique needs of low vision individuals who are very young, older, and/or have multiple disabilities.

Functional Epidemiology of Low Vision

We identified a significant need for more epidemiological studies that use functional task-based measures of visual performance. Most available epidemiological data on vision loss is in terms of disease categories, or, if any functional measure is reported at all, as visual acuity alone. But low vision interventions address functional categories, including extent and impact of impairments involving the visual field, contrast sensitivity, existence of preferred retinal locus, reading acuity and reading speed, sensitivity to crowding, spatial orientation, etc. It is, unfortunately, not possible to obtain functional data from most existing eye studies, which generally use clinical diagnostic measures rather than functional categories. One way to address task-based visual function in the absence of the resources for direct psychophysical measurement of performance is through the use of questionnaires and other self-reporting techniques.

However, we note an important point for all functional measures of performance: tasks may have very different significance to the individual depending on region, economic status, culture, and so forth. They must, in most cases, be defined specifically and appropriately for the locale in question. Loss of reading ability, often considered to be the most devastating implication of visual impairment in developed nations, may have far less significance and impact on quality of life in some regions where illiteracy rates are high in the general population. Family and other social structures, and attitudes toward aging and disability, may require special choices for outcome measures. Such studies are necessary to identify the most prevalent functional categories. This is also of critical importance in outcome studies (see below).

The WHO's International Classification of Functioning, Disability, and Health (ICF) is one attempt to provide a culturally neutral classification of functioning, but as yet has not

been extensively applied to research for visual function. It is a classification system, however, and not an assessment instrument, and as yet there is no accepted method for applying it to visual assessment data.

Access to the built environment, to communications media and to rehabilitative measures that insure a quality of life is, in our view, a civil right. But data that show the economic benefits to society of low vision care is at least as convincing as civil rights arguments, to governments and insurers, who provide most of the financial resources to provide the access. As long as epidemiological studies count people only in terms of disease and simple functional measures such as visual acuity, those possessing the resources to develop global low vision interventions will not be convinced of the value of addressing the global low vision problem. More persuasive would be studies that count people in terms of functional effects of low vision and which can show that reducing the negative impact of low vision through education and rehabilitation reduces the overall cost to society. The economic cost to a few, specific countries has been estimated and these suggest that the cost to a country even the size of Australia may be counted in the billions of dollars (Access Economics Pty Limited, 2004). However, more extensive work needs to be done to refine the methodology and produce results which can be generalized cross-culturally.

Outcome Studies: The Evidence Base for Low Vision Services

There is a pressing need for high quality outcomes research in nearly all areas of low vision services, to identify which specific low vision services are effective. While there are quite a few studies in the literature that examine outcomes, few of them use the multi-center and randomized designs that have come to be the standard for clinical trials in medical outcomes research, and which appear to be necessary in convincing government regulators and insurers of treatment effectiveness, and which are clearly useful in evaluating cost of providing services against benefit to society (e.g. Access Economics Pty Limited, 2004; e.g. Frick & Foster, 2003). Such studies are, of course, expensive to conduct, but we consider that they are as important as traditional medically based clinical trials.

General outcome studies are particularly needed to address, with respect to quality of life measures, the effectiveness of:

- optometric/ophthalmologic low vision rehabilitation interventions
- specific types of optical, non-optical, and electronic low vision devices and their use
- training in the use of low vision devices, including training of required motor skills
- training in eccentric viewing techniques

- orientation and mobility training
- rehabilitation teaching
- psychological and social work counseling
- the impact of optical device and visual efficiency instruction on educational outcomes in children

In addition, comparison outcome studies are needed to identify:

- best practices in assessment and device prescription, including analyses of why prescriptions vary systematically according to local custom even where cost is not a barrier. For example, high plus lenses tend to be prescribed less in the Netherlands than telescopes; hand and stand magnifiers tend to be prescribed more than spectacle magnifiers in the U.K.
- best practices in teaching low vision professionals, even though this may be quite different in different parts of the world, especially with respect to different cultures, resources and funds available.

Much of this outcomes research relies on the existence of good quality of life measures, which need to be translated and/or adapted from existing ones. However, since existing measures are likely to be culturally biased, reflecting the values of the developed nations in which they were developed, it is likely that new ones will need to be developed for use with various cultures and age groups.

Research and Development (R&D)

We identified the following specific needs in R&D:

- New technologies that can be used in new low vision devices are important to pursue. Since the market for such devices tends to be relatively small, government funding agencies should set aside funds for this purpose.
- Development of minimum standards of quality for new and improved devices. This is especially important for development of new low-cost devices in the developing world.
- Standardized and validated assessment instruments that can be used worldwide. A low-cost visual field test was identified as one particular such need, as are different versions of assessment tools such as reading performance tests that use alphabets other than the Latin alphabet.

Other Significant Research Issues

- Research on barriers to identification of those in need of low vision services, including attitudes of the general public, employers, educators, consumers with low vision, gender roles in low vision, cultural attitudes about vision loss, privacy and independence.
- Identifying who among those with good access to low vision services often do not seek them, and why.
- Identifying the circumstances (in addition to visual acuity and visual field extent) under which individuals will prefer to perform a task tactually or verbally rather than visually.
- Research on eye movements in low vision.
- Research into functional use of vision for those with very low vision, most of who are typically categorized as blind (i.e., acuity $< 3/60$). Little is currently known about very low vision, and as medical treatments for blindness advances including retinal chip implants and other methods of artificial vision systems, we may see an increase in the number of individuals with very low vision.
- Human factors research into how those with low vision interact with the built environment. For example, what font sizes, letter sizes, and color contrasts make visual signs accessible to what proportion of the low vision population? How can the accessibility of environmental features such as staircases and escalators be improved for persons with low vision? What wayfinding strategies are most effective when street signs and room signs cannot be read visually?
- Research on the psychosocial impact of low vision.
- Research on low vision resulting from combat in war-torn areas (mainly traumatic brain injury) and from economic sanctions.
- Research on how congenital low vision impacts the development of children.

A Call to Action

We call here for internationally coordinated action by governments, NGOs, individuals with low vision, eye care and rehabilitation professional organizations, and other stakeholders to raise awareness of low vision, increase resources for low vision research, education and rehabilitation, and include these into global healthcare and education initiatives. Even in the developed nations, there are still many areas where low vision services are simply not available or accessible, and the problem is obviously much worse

in the developing nations. Recognizing that existing initiatives to diminish blindness already incorporate low vision within an overall blindness prevention strategy, we endorse these efforts, but recommend that they be expanded and separated out when appropriate, especially in areas outside of the traditional health care system. Given difficulties in defining and separating the terms “blindness” and “low vision” and the large functional overlap between those who are considered blind and those who are considered to have low vision, we advocate the expansion of the current global initiative to reduce preventable blindness to include the reduction of the unnecessary and avoidable impairment caused by the lack of services for those with low vision. Available evidence suggests that such an expanded initiative is cost-effective and a readily initiated complement to the existing Vision 2020 initiative.

The Vision 2020 initiative, which has done an admirable job of unifying the efforts of its many supporting organizational members, already has a mechanism in place for implementing the international blindness prevention effort at the national and district levels (see <http://www.v2020.org/toolkit/start.htm>) and many locales are now implementing these. Our Call to Action includes a plea to the Vision 2020 initiative to incorporate reducing the impact of low vision into their plan as a much stronger and more visible element, one that stands alongside rather than being a subcategory of blindness prevention.

Low vision services are completely compatible with blindness prevention, and can be viewed as a means of optimizing task performance with available, even though reduced, visual resources. In contrast to the old sight conservation concept, predominant in the developed nations even well into the 20th century, in which it was believed that using the impaired visual system would result in further damage, encouraging the development and use of vision can be thought of as encouraging the physical and mental development of children and the maintenance of visual skills in adults with acquired visual impairments.

Those with normal vision sometimes perform visually at threshold, and in reduced visibility conditions (e.g., in fog or at night), and indeed, much of visual experience is cognitive construction of a mental visual world from sparse retinal information. Normal vision and low vision are both, in many ways, functions in which spatial tasks are solved with whatever optical information is available through the eyes. Low vision is similar to normal vision; the main difference is that there is less optical information available, from diminished contrast, visual field, or other image degradation.

Prevention of visual disability, then, can be viewed as the central goal, with blindness prevention and prevention of excess disability through low vision services, as the means to accomplish that goal. In simpler terms, we wish not only to prevent blindness, but also to prevent those who have sufficient vision to accomplish tasks visually and who wish to do so from being treated and educated as blind and therefore prevented from using the single most important sense for accessing the visual world. Thus the central theme of our Call to Action is to elevate prevention of needless disability from low vision to the same level of urgency as blindness prevention.

While we endorse principles of research-based practice and include an evidence base for low vision services within our research agenda, we also acknowledge that much of the data are still insufficient to convince governments and other service payers of the effectiveness of services. While we need more hard evidence, the success of low vision programs, where they have thus far been implemented, in enhancing quality of life, is widely accepted within the professional community. Moreover, successful programs have already been developed within such culturally diverse countries as Pakistan and Australia. Therefore, we recommend that implementers of eye care and public education programs move forward to reduce the global impact of low vision as outlined below, and use research data on outcomes as well as good examples of service delivery to refine program structures.

Steps required in a regional action plan:

1. Identify stakeholders including government agencies representing health and education, professional organizations and service providers at all levels, financially interested parties such as governmental and third-party insurers, and manufacturers, distributors and retailers of low vision devices. Some stakeholders may represent the interests of the low vision population but have a substantially different main population, e.g., some blind consumer and/or rehabilitation organizations, organizations representing seniors, etc., involve all stakeholders in the plan for action.
2. Identify which providers of low vision services can perform low vision services effectively and economically without rigid and preconceived ideas about which professionals are most appropriate, especially when those ideas are based on models from other cultures. Attempting to create an optometric system, for example, in a nation that does not use optometrists, is likely to be less effective than engaging the profession that currently carries out what is known elsewhere as optometric low vision. Restructuring of the health care or education systems to create new professional categories should only be done if there is a lack of service, and where this is necessary the process can be most expeditiously accomplished by utilizing existing models developed in other countries.
3. Encourage the formation of consumer advocacy groups and NGO's dedicated to low vision. At Oslo, we observed that there are almost no such organizations anywhere. Virtually all organizations that represent the interests of the low vision community are blindness organizations. We speculated that consumers with low vision, most of whom acquire low vision late in life, do not generally identify themselves as "culturally" blind, nor even as visually-impaired. Evidence for this view exists in the many countries where consumer groups of the blind formed early in the last century, whereas groups of low vision consumers have formed only in the past 15 to 20 years. Many do tend to identify themselves as patients with a particular visual disorder, and do join consumer groups centered around an

eye disease. Examples of consumer organizations that advocate primarily for a population with low vision are those that are interested in such conditions as albinism and age-related macular degeneration. For low vision consumers to have a political voice that effects social change on attitudes toward low vision, there will need to be either a group of advocacy groups representing different consumers with different eye diseases, or a grassroots effort to form a political voice for low vision consumers and advocates. For a truly global voice to be provided to individuals with low vision, an organization comparable to the World Blind Union may need to form.

4. Public awareness campaigns are sorely needed not only to identify people with low vision for service, but also to change society's image of the person with low vision. These campaigns can also make behaviors such as very close viewing, and use of magnifiers and other equipment, better understood by the public, similar to the way that wheelchair use has become a more typical sight in urban life, advertising and other public media. One way to establish such campaigns is to dedicate some World Sight days to low vision and prevention of excess vision disability.
5. Low vision needs to be added to the curricula of all professions whose members come in contact with people with low vision, including all eye care fields, education, most general medical education, and rehabilitation personnel where rehabilitation systems exist.

Summary and Conclusions

The participants of the workshop met to discuss and to develop strategies that would focus on the delivery of low vision services in developed and developing nations, address the world wide need to bring low vision into the public conscience, and to develop a research agenda relevant to low vision populations and services. From the start, we drew a distinction between those who can benefit from efforts directed toward low vision from those directed toward blindness. Although we acknowledge that definitions of legal blindness include many people with low vision, we also note that an even larger number of people with low vision are not considered blind by these same definitions. At the meeting, we adopted a definition of low vision that more appropriately reflects the scope of visually functioning people who have impaired vision.

We also acknowledge that there are efforts underway by respected NGOs and international agencies that are directed at the prevention of blindness; many of these efforts include work toward eliminating some of the problems caused by low vision. However, it was also emphasized that there is a need to elevate the needs of people with low vision alongside those efforts to prevent people from becoming blind and those efforts directed toward education and rehabilitation of those who cannot use functional vision.

As different nations have different levels of financial resources devoted to populations with visual impairments, including those with functional or total blindness and those with low vision, a very general framework of low vision service delivery was discussed, developed, and extended. The participants strongly believed that ability to use one's vision must be assured through access to low vision services. The participants considered this access to be a human right and equally important as the development of services and methodology for becoming independent through non-visual modalities for those who are blind. There was a further discussion that when the use of sight is preferred or if the individual wishes to combine visual with other modalities for task performance, that providing the means to access the visual environment is the responsibility of professionals who are experts in low vision care. As professional knowledge is needed, the participants also called for the training of all personnel who work with low vision populations to have in their training curricula content, that separates services planned for those with low vision from those who are blind.

The participants also called for design features in the built environment that would enable people with low vision to use visual cues. For example, signage should consider the needs of individuals with low vision for ease of travel. It was also noted that such design considerations would improve the visual environment for sighted individuals in cases of reduced illumination or poor weather, as well as for the "normally" sighted elderly whose aging eyes find it difficult to traverse complex, poorly designed environments.

Education systems and rehabilitation systems are called upon to address the needs of those who have low vision in their general and specific services. In other words, children with low vision should have access to education offered to all children with appropriate adaptations. Rehabilitation systems, where available, should provide services that are appropriate to those with low vision without channeling them into services for those experiencing functional or total blindness.

Health care systems should also consider and plan for populations with low vision. Services directed to those who are blind may not meet the needs of low vision populations and may leave the low vision population with inappropriate services or a desire not to access services. Special considerations may be needed to include the elderly who are experiencing age-related visual conditions that result in low vision.

On considering an appropriate research agenda, we looked first to the need for epidemiological studies that can provide empirical support for the global need for low vision services. We noted that while there are quite a few large population studies of visual disorders, few contained functional data beyond visual acuities. We concluded that visual acuities and disease entities alone were insufficient for the planning, delivery of, or support for low vision services, and that a broader array of functional studies is needed.

Intervention and outcome studies were called for in diverse topical areas including, but not limited to, general optometric/ophthalmologic interventions, the effectiveness of specific optical devices, and the psychological impact of congenital and acquired low vision. Also, the participants considered comparative outcome studies to have national and international implications. Best practices for the preparation of low vision personnel and the use of assessments and device prescriptions were among the suggested topics. Further, the participants called for funds to be allocated for research and development efforts. These included but were not limited to new technologies for optical and non-optical devices, the development of standards for new and low cost devices, and the development of validated instruments for assessments were among the examples given. As people live longer, many countries must prepare for great increases in populations with age-related conditions that result in low vision. Research in war-torn areas was another concern of the participants as it was understood that wars result in cortical and other trauma-induced causes of low vision.

A worldwide Call to Action was the third focus of the workshop. There is a need to convince governments and other service payers of the human and cost benefits of providing low vision services. The message that the provision of low vision services may prevent continuing or increased levels of disability must be given to general, as well as professional, populations of all nations. As a result more people with low vision may understand that while there may be little more that medical care may afford in terms of cure, there are services that may allow for a better quality of life, education, and employability. As more people know that such services are available, and that using the devices may become more accepted and commonplace (similar to seeing support canes and wheelchairs in public), the more people may desire and obtain appropriate care.

This Call may also be realized by encouraging all international efforts toward blindness prevention to recognize the needs of those whose visual conditions result in low vision. The Vision 2020 initiative supported by many international organizations was especially called upon to raise the components of their initiative directed toward low vision care alongside, rather than subsumed within, their efforts for blindness prevention.

In conclusion, the participants identified a five-step action plan to operationalize the ideas and strategies that could result in a reduction of the global impact of low vision. This plan may only be as effective as the continuing and necessary follow-up efforts to this historic meeting. When professionals and consumers from many nations and regions of the world, and representatives of international organizations and NGOs met to discuss the worldwide low vision population, it was their dream that the use of functional vision would become a human right and one to which a worldwide effort would soon be engaged.

References

- Access Economics Pty Limited. (2004). *Clear insight - the economic impact and cost of vision loss in australia*. Melbourne: Centre for Eye Research Australia.
- Frick, K. D., & Foster, A. (2003). The magnitude and cost of global blindness: An increasing problem that can be alleviated. *Am J Ophthalmol*, 135(4), 471-476.
- Pararagasegaram, R. (2004). Low vision care: The need to maximize visual potential. *Community Eye Health*, 17(49), 1-2.
- Resnikoff, S., Pascolini, D., Etya'ale, D., Kocur, I., Pararajasegaram, R., Pokharel, G. P., et al. (2004). Global data on visual impairment in the year 2002. *Bulletin of the World Health Organization*, 82, 844-851.
- World Health Organization. (1992). *Management of low vision in children: Report of a WHO consultation*. Paper presented at the July 1992 WHO/PBL Consultation, Bangkok.
- World Health Organization. (1996). *Low vision care for the elderly*. Paper presented at the Workshop of WHO/PBL/96.57, Madrid.
- World Health Organization. (2001). *Asia pacific regional low vision workshop*. Paper presented at the Asia Pacific Regional Low Vision Workshop, Hong Kong.

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