

## Reducing the Impact of Low Vision around the World

Aries Arditi

The International Society for Low Vision Research and Rehabilitation

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The lack of low vision services has heavy costs to both individuals and society . Because the relationship between low vision and blindness has only recently been well understood, low vision has received little attention worldwide despite the fact that the vast majority of visually-impaired people have low vision . This talk describes a) a framework for low vision service delivery to describe existing services throughout the world and to propose improvements within existing medical, educational, and rehabilitation facilities, and the development of new services where they currently are within reach or do not exist in both developed or developing nations, b) 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 sound research, and c) an international call to action for governments, Nongovernment organizations (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.

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### Introduction

Much of what I will say today stems from a workshop that I had the great pleasure of organizing, along with Anne Corn, Krister Inde and Gregory Goodrich . And that took place over five days in October of 2004, in Oslo, Norway . Twenty-five experts from around the world met there to address how to reduce the impact of the global explosion in the number of people with low vision that is expected in the coming decades .

We also produced a report, and the report may be downloaded from the ISLRR site (<http://www.islrr.org/Oslo%20Workshop%20Report.pdf>); I encourage you to download it and read it . We are looking for someone to translate the report into Japanese, so if you would be willing to do so, please let me know (Mr. Morio Sugai of Japan Guide Dog Association had volunteered to do the translation during the joint meeting.) .

Figure 1 shows the twenty-five of us, outside the Rehabilitation Center where the workshop took place . We had ophthalmologists, optometrists, rehabilitation teachers, entrepreneurs, psychologists, social workers, administrators - nearly every discipline that works in low vision rehabilitation, from all corners of the globe - and we

understood that our first goal was to forget our professions and our professional egos . There are many places in the world, particularly in the developing world, where health care is so basic that it is performed, only by community health workers . Even in the developed world, professional categories vary widely from nation to nation, so what is done by ophthalmologists in one part of the world may be done by optometrists and even rehabilitation workers in other parts of the world .

In order to insure that we worked hard, we arranged to have bad weather for the entire five days of the workshop.



Figure 1. Photograph of participants in Oslo workshop

We addressed many themes at our workshop and looked at the state of low vision rehabilitation around the world . Today I would like to focus on just a few of these themes, which I believe, are important in every culture, and are important to consider for the world as a whole.

The themes I want to emphasize today are problems, in

- Defining low vision
- The size of the low vision population
- Low vision in relation to blindness
- Low vision services as
  - a civil right
  - economically sensible for society to provide

## **Definition of Low Vision**

### **1. Definition for Understanding**

“Reduced ability to carry out life’s activities due to uncorrectable, but partial vision loss . Substantial usable vision remains .”

I think probably everyone in this room shares a similar informal definition of low vision as this one: Reduced ability to carry out life’s activities due to uncorrectable, but partial vision loss . A key element, of course is that substantial usable vision remains . Most professionals recognize that since everyone’s circumstances and needs are unique, low vision should not be defined any more specifically than this to perform effective rehabilitation .

### **2. Definition for quantification**

But if we want to count the number of people with low vision around the world, we need to adopt a more quantitative definition . The one that we came up with in Oslo is this one:

“Visual acuity ranging from 6/18 (20/60) to light perception in better eye

OR

Visual field whose extent in all directions around fovea <10 degrees in eye with greater central extent must use or be potentially able to use vision for planning or execution of a task .”

It is similar in spirit, but superior to the definition developed at a meeting in Bangkok some years ago by members of a World Health Organization (WHO) task force . Under this definition, one has low vision if they have

Visual acuity ranging from 6/18 (20/60) to light perception in better eye

OR

Visual field whose extent in all directions around fovea <10 degrees in eye with greater central extent

Again, it is key that they must use or be potentially able to use vision for planning or execution of a task . This definition includes many people who are considered blind, at least by legal definitions .

Nearly every locality has some kind of legal definition of blindness . In the United States it is 20/200 (6/60) or a visual field extent of 20 degrees in the better eye . The WHO defines blindness as 20/400 (6/120) . In the field of low vision rehabilitation, we know that there are many people who meet the definition of blindness who also meet our quantitative definition of low vision and can use their vision very effectively.

### **3. Problems with Legal Blindness**

There are problems with legal blindness definitions, which tend to divide the world into those who can see and those who cannot see, with nothing in between . Another problem is that, legal blindness actually includes more people with low vision than people who cannot use their vision to perform tasks . Finally, it causes many of those with low vision to either call themselves blind, or if they are uncomfortable with that label, they may deny their vision problem altogether .

But legal definitions are extremely difficult to change.

### **4. Difficulties in fixing the legal blindness problem**

First, the social benefits people receive depend on the definition, and this is inherently difficult to change.

Second, we must admit that in our own field of vision rehabilitation, it is easier to raise money for blindness, which everyone fears, than for low vision, which few people understand .

Indeed it often serves our purposes better if we can raise money to help the blind, and include the much larger numbers of legally blind people in our counts, rather than the small numbers of totally blind people.

### **5. Low vision is more prevalent than blindness**

As we in this room know, there are many many more people who have low vision, even using conservative numbers than totally blind.

Figure 2 shows an estimate of the number of people with low vision worldwide using our Oslo definition compared to those who are totally blind, using estimates from the WHO and reasonable assumptions, also published by WHO . There are roughly 61 million people in the world who meet a conservative definition of low vision—this number does not include those with refractive errors or cataract; there are probably less than 7 million who have no vision, or just light perception.

The confusion about what low vision is, and how preva-

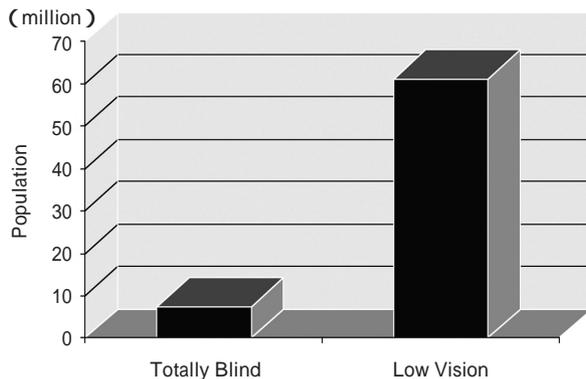


Figure 2. Estimated number of population with blindness and low vision

lent it is, to the general public and to health care service delivery systems around the world has a huge impact on all individuals with low vision.

### Low Vision Service Delivery

And sadly, low vision service delivery is still very basic: For only a small minority comprehensive low vision services readily available . For others services are available but inadequate .

For some, low vision services use only techniques for those without sight . For many services are completely nonexistent.

#### 1. Impact of No Services

I do not need to remind this audience that the impact of no services has very negative effects on those with moderate and severe low vision . Often it results in social isolation, dependency and inability to participate in family and society . Additionally, in children, having no services is associated with developmental delays, loss of educational opportunities, and difficulties in social development . For adults, having no services often means unemployment or underemployment which are far more costly to society than the services would be, loss of privacy and especially for older people, potentially increased risk for psychological and health effects, and even mortality.

#### 2. Model and Advantages of Service Delivery

In Oslo, we developed a generalized model of service delivery, that is an extension of a model developed by the WHO and that is serving as a model for the Vision 2020 Initiative . I will not go into that model today for lack of time, but you can read about it in the workshop document.

For now, I note simply that the benefits of providing low vision services, are that it gives the individual: Participation

in family and society structure, Independence, Educational and economic opportunity, Increased contribution to society, Reduced social and economic burden to self, family, society.

### 3. Research Agenda for Low Vision

Another thing we did in Oslo was to develop an agenda for low vision research . We do not envision this as a plan for all research, but rather to develop a research base that would support national and international advocacy efforts that form the basis of both civil rights and economic arguments in favor of low vision rehabilitation . I will highlight three types of needed studies: Functional epidemiology of low vision, outcome studies as an evidence base, and psychosocial and cultural factors.

#### 1) Functional epidemiology of low vision

First, the functional epidemiology of low vision . Nearly all epidemiological studies reported in the literature are disorder or disease based, and those that describe visual function at all, invariably use only visual acuity .

We need performance-based studies that describe function using tasks for clinical assessment such as visual field, contrast sensitivity, preferred retinal locus (PRL), sensitivity to crowding, and so on .

We also need studies that describe function in terms of tasks important for daily living, such as reading acuity, reading speed, and spatial orientation . Culture, region, and economic status must all be taken into account . Such studies are crucial for providing an evidence base to establish the magnitude of the low vision problem, that is useful in advocating to governments and other funding sources.

#### 2) Outcome studies as evidence base for low vision services

There is a pressing need for high quality outcome studies, to know what kinds of interventions work and which ones work best, and to gauge the benefit to society against the cost of providing services . Such studies are expensive to conduct, but they are as important as traditional medical outcome studies.

In my country it is relatively easy to get research money to do a clinical trial of a new drug; but it is exceedingly difficult to get money to test the effectiveness of a vision rehabilitation intervention . Why?

Specific outcome studies that are needed include:

- (1) Optometric/ophthalmologic interventions
- (2) Specific types of devices and their use
- (3) Training in the device use, including motor skills
- (4) Training in eccentric viewing techniques
- (5) Orientation and mobility training
- (6) Rehabilitation teaching

- (7) Psychological and social work counseling
- (8) Impact of device and visual efficiency on educational outcome
- 3) Psychosocial and cultural factors

Finally, we need to study the following: As barriers to identification of those in need of service, (1)Attitudes of employers, consumers, educators, and general public, (2) Gender roles, (3)Cultural factors, (4)Privacy, and (5) Independence . Also we need identification of those who do not seek service and why .

### A Call to Action

Our final goal in Oslo was to develop a call to action, to be conducted in a coordinated fashion by international coordinated action by Governments, Nongovernment organizations, Individuals with low vision, Eye Care Professionals, Rehabilitation Professionals . We need to identify stakeholders all over the globe who can help us raise awareness of low vision, increase resources for research, education and rehabilitation, include all this into global healthcare programs and educational initiatives.

It is important to consider the cost . Developing countries can begin with lowcost devices, and build low vision services into their developing health care structure from the ground up . Note that many developed countries have undeveloped low vision services.

#### 1. The Vision 2020 Initiative

I am sure that most if not all of you are aware of the Vision 2020 Initiative . Jointly sponsored by the International Agency for the Prevention of Blindness (IAPB) and the WHO, this initiative has as its stated goal to eliminate avoidable blindness throughout the world by the year 2020 . The initiative has low vision programs in

its regional plans, and this, of course is very good . The Oslo Workshop found that this program was very well organized and would result in global expansion of low vision services especially in the developing world.

The only problem we found with the initiative was that low vision should be a much stronger and more visible element . Low vision should not be a subcategory of blindness prevention, because as I indicated earlier, most people who are considered blind, even by the WHO definition, actually have substantial usable vision . To address low vision within an overall blindness prevention strategy is to send a confusing message to the public, and again, to characterize all people as either sighted or blind. We are sending a plea to the Vision 2020 Initiative, instead to promote their program as prevention of vision disability, which includes both blindness and low vision . We hope they will hear our plea and clarify their message to the world.

#### 2. Elements of an Action Plan

Most of what Vision 2020 is doing, they are doing right! Their plan is entirely consistent in its actions with what we found in Oslo, including

- finding stakeholders at all levels (including service providers and entrepreneurs)
- identifying service providers within each nation and culture that can work efficiently and give up rigid ideas and professional territorialism
- encouraging formation of consumer advocacy groups that can give low vision consumers the voice that they currently lack worldwide.

We need

- Integration of low vision into the curricula of all professions who come in contact with those who have low vision, including educators, and general medical



Figure 3. Scene where a person is using a magnifier

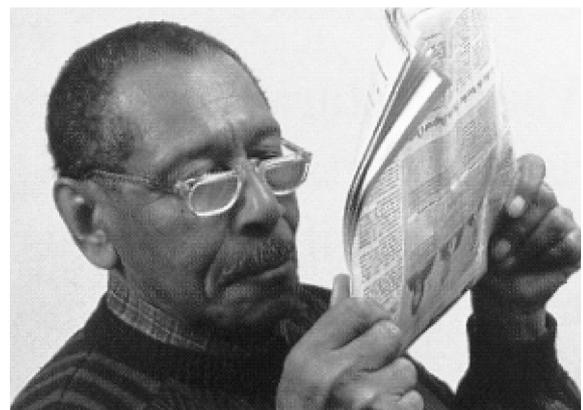


Figure 4. Behavior of very close reading

practitioners, social workers, etc.

- Public awareness campaigns to change society's image of persons with low vision so that images such as these, of people using magnifiers, and reading at very close distances will not seem odd to the general public (Figures 3,4) .

## **Conclusion**

### **1. Meaning of Success**

In closing, let me say specifically what success in reducing the global impact of low vision means:

First, it means that low vision services will be available to anyone who can benefit from them .

Second, it means that the general public will understand what low vision is, as distinct from blindness and normal vision .

Third, it means that the use of low vision aids, and the behaviors needed in low vision such as close reading, will be a common and acceptable sight .

## **Acknowledgement**

I am honored to be here at what I understand is the very first joint meeting of the Japanese Society for Low-vision Research and Rehabilitation with the Japanese Association for Rehabilitation of the Visually Impaired . It is an honor not only because of the prestige of both organizations, but also because this joint activity represents the kind of collaboration the world needs to address the global problem of low vision.

I want to begin by thanking several people:

First, the organizers of the meeting, Dr. Yoshitaka Yamagata and Mr. Tohru Nakamura .

Also, Mr. Koichi Oda, who now sits on the Executive Committee of the International Society for Low-vision Research and Rehabilitation, and whom I have known for many years . Dr. Kenji Yanashima, whom I also have had the pleasure of knowing for six years, and who has given two terms of service on the ISLRR Executive Committee.

And finally, Dr. Akio Tabuchi, President of the JSLRR who I had the great pleasure of meeting here in Kobe in 2001.

Mr. Ryota Fukui of Japan Guide Dog Association undertook the interpretation during Dr. Aries' special lecture and also contributed to the translation of this article.