

# Sight Enhancement Services — A Safety Net or a Spider's Web?

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## 1. Sight Enhancement Services

This paper will review the development of the "human services" aspect of sight enhancement, and the integral role of human services in an effective and comprehensive sight enhancement system.

First, what exactly is meant by human services? Briefly, it is the organized capacity of people to care for one another through organizations or social institutions — how we as a society offer love, compassion and help to members of our society and the world at large. With regard to sight enhancement, human services are those rehabilitation, counselling, educational and leisure services that allow individuals the freedom to attain their potential and to participate fully in society. Important as these human services are, they cannot be offered in isolation from the diagnostic and remedial assistance provided by vision health practitioners and specialists.

The use of the term "blind" refers to persons without any vision at all, while at the same time, there is a close association between blind persons and those whose vision is extremely poor, or is failing rapidly.

Early reference to care and compassion for blind persons is found in the book of Leviticus: "Thou shalt not ... put a stumblingblock before the blind." In the 14th century attempts were made to allow blind persons to read, but five centuries were to pass before Louis Braille's embossed system was to remove the barrier of illiteracy.

From this point Western societies were to witness the evolution of organized human services for the blind and visually impaired. Braille's system was truly the key to organized human services for the blind as they exist today. This evolution began with the development of schools for the blind. The first school for the blind in Canada was established in 1861, but over half a century passed before the CNIB as a service organization received its charter in March of 1918. CNIB proved to be a unique approach to human and rehabilitative services given that it is a national service organization. Contrasted to other developed countries, CNIB represents a most interesting approach, and one that is envied by other organizations involved in human services in this country and elsewhere.

The Canadian National Institute for the Blind — the CNIB — is a complex rehabilitation organization providing a wide range of human services. While the CNIB has only recently become involved on an expanded scale with the new Sight Enhancement Program for visually impaired individuals, its goal

has always been to help blind, visually impaired and blind multi-sensory-deprived individuals find ways to lead productive and satisfying lives. The concern has always been with the whole person, and not just his or her lack of vision.

As the needs and expectations of the blind and visually impaired population changed, and as society has become more interested in the rights of disabled individuals, this concern has taken a number of forms. The CNIB began by providing rehabilitation services and training and worked to educate the public while lobbying the government at all levels. This approach paid off through legislation, including disability pensions, public health measures, Income Tax Act exemptions, and White Cane Acts. The CNIB not only employed blind and visually impaired persons, but built residences and service centers. In 1968 the CNIB established a national vocational guidance and training centre, a decision that in retrospect was at variance with today's trend to community-based services and programs.

Today the CNIB has only a few residences for elderly blind persons remaining, as public and private sectors in Canada have assumed responsibility for providing services in local communities.

From its inception the CNIB has promoted consumer participation in decision-making. Today the public has become sensitized to the problems of the disabled, and organizations of the disabled have achieved a stronger influence in decision-making, planning and implementation of services directed at them, and in numerous initiatives to secure general and specific human rights.

This trend will continue, along with decentralization of service, and partnerships between government, service organizations, and consumer groups in this field. The consumer — the individual consumer — is going to have an increasing say, not only in what service is provided, but in how, where and when it is provided. To keep in touch with and respond to the needs of this fast-changing market, service providers are going to have to step up their sensitivity to and understanding of the environment with increased penetration and analysis of the "consumer" impact. Planned co-ordination of human and sight enhancement services will become even more important if service providers hope to deliver responsive, efficient and useful service to our constituency.

Some of these trends are worrisome given the risk of fragmentation and duplication and CNIB has become one of the players in an ever-expanding network of professional organizations. But CNIB, because of its concern with human services and with its firm goal of helping individuals with impaired vision achieve their full potential, must ensure that individuals are receiving the service they need, and that the complex network



helps rather than hinders their attempts to take their place in society.

Before addressing the issue of the sight enhancement system or network in Canada, a brief description of CNIB's expanded sight enhancement policy and program is required.

In 1985 CNIB served 46,000 individuals of whom approximately 10 per cent (or 4,636) were new registrants. Figure 1 depicts the dramatic increase in the number of registrants from 1969 to 1985 — more than 68 per cent. This registered group is comprised of individuals who fall within the 6/60 (20/200) or less category, often referred to as "legally blind". In fact, 90 per cent do have a degree of residual vision.

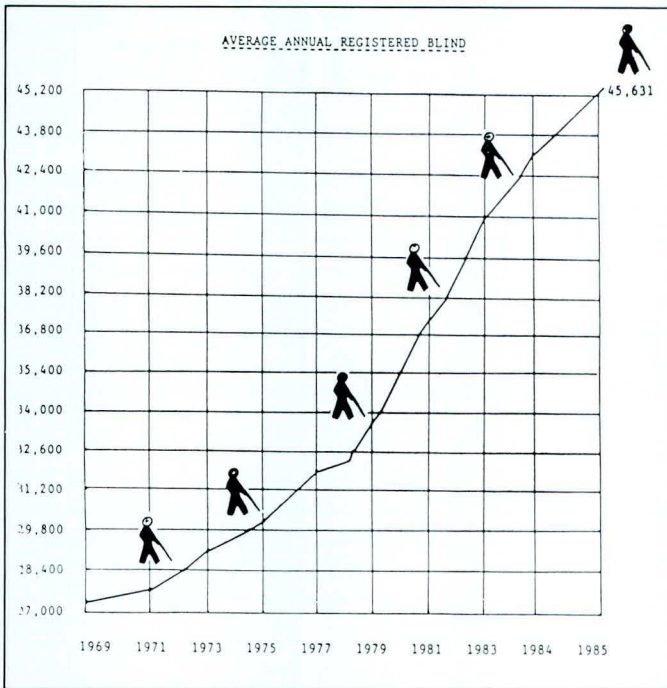


Figure 1

Globally, the number of blind persons is expected to increase from 42 million in 1978 to 100 million by the year 2000. The prevalence of blindness in Canada and other developed countries is approximately 222 cases per hundred thousand people, compared to as many as 5,000 per hundred thousand in developing countries. The prevalence of blindness for developed countries supports our projection of a total of 55,000 people eligible for registration with CNIB. However, if the scope of what is considered severe visual impairment is broadened from 6/60 (20/200) or 10 per cent vision or less to 6/21 (20/70) or less, the number of potential registrants for CNIB services increases by 195,000. Altogether, there may be 250,000 people in Canada who might benefit from Sight Enhancement Services, although by no stretch of the imagination would all these people require assistance, nor would CNIB have the capacity to serve them.

It is for this group, those whose visual impairment is not severe enough to be considered blindness as the term is usually defined, but whose sight is poor enough to create practical or functional problems, emotional stress and family difficulties, for whom CNIB has recently developed a new sight enhancement policy and launched a new program, Sight Enhancement Enterprise (SEE).

Through SEE, every person wishing to optimize his or her remaining sight can be trained in the best use of this residual

vision and will have access to the most advanced technological products. Our first priority is and will continue to be those with no vision or extremely poor vision, the deaf-blind and the multi-handicapped. It is this group which the CNIB will serve first and always.

Anyone with a vision problem can approach any of the 50 offices of CNIB across Canada for counselling, rehabilitation services, or referral to other community services. The program will be a co-operative effort involving health practitioners and education and social service personnel from the private and public sectors.

In short, SEE is about rehabilitation. It is designed to reduce the impact of disabling and handicapping conditions, with the objectives of enabling the disabled and the handicapped to achieve social integration and full participation. The importance of such rehabilitation is well documented: visual impairment, along with other disabilities, causes society to incur high costs, both social and economic. Rehabilitation and support programs can significantly reduce these costs, and better still, prevention can avoid them altogether. The bottom line of course, goes back

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to human services and the organized capacity of people to care for one another and help each other to lead satisfying lives.

Two aspects of the SEE program are of special note. First, every one of the 50 CNIB offices will have a range of technical aids on display, and 14 major display centers across the country are now being developed. Individuals with vision problems will have the opportunity to try new technical aids, to borrow them and to receive training.

The second aspect is service to seniors. Today, nearly 60 per cent of the people registered with the CNIB are over 65 years of age, compared to about 45 per cent only 10 years ago. Since 1971, when CNIB registered 1,100 new persons over 65, the number of new registrants over 65 each year has climbed 300 per cent to 3,300. That 3,300 represents 72 per cent of the new registrants in 1985. It underlines the fact that the population of older people, here and in the rest of the world, is growing at a tremendous rate, and is going to have considerable impact on health systems, including sight enhancement.

Loss of vision usually occurs slowly, over time, and may not be noticed by the individual, his family or his friends. However, loss of vision can have a devastating effect on an individual. Low vision aids have on occasion had impressive results with older people who had been mislabeled "confused" or "depressed" when the real problem was that they could no longer see well.

Sight enhancement services for the elderly are particularly important because they can mean the difference between independence and institutionalization. The price we have paid for industrialization in the developing world is the erosion of



the nuclear family. This is in stark contrast to stronger family ties in the developing world. In Western society we are more dependent on the safety net. Loss of vision often forces an individual to give up his or her home and ultimately to lose independence. And since independence is one of the best measures of quality of life, the role of sight enhancement services in maintaining independence is crucial.

The Sight Enhancement Enterprise Program, and CNIB itself, are today just one part of the complex network of low vision services in Canada portrayed in Fig. 2. At the centre, of course, is the consumer, the person with poor or failing vision. Next is the resource system — optometry, ophthalmology, medical doctors, public health nurses, hospitals, university clinics, vocational rehabilitation services, assistive devices, research groups, consumer groups, volunteers and other services and organizations such as the CNIB. Next is the information system, which attempts to connect consumers with the services available. This includes the media, association newsletters, government publications, libraries, consumer organizations, and so on.

It is a good system, it is a thorough system, and in Canada there are a minimum of 45,000 points of entry to obtain rehabilitative, medical and the entire range of sight enhancement services. For North America as a whole, the evidence suggests approximately half a million points of entry. There exists enough entry points to the system to ensure access for everyone in Canada or North America who needs assistance. But the question is, does it? Does the system ensure access to appropriate service? Unfortunately, the answer is no, not always. It doesn't take much discussion with the consumers, with the users of the system, the people who are supposed to benefit, to discover problems with this very complex system. In other words, the safety net could be described as functioning more like the spider's web where you are caught in the system rather than helped by it.

Too commonly, one of the first problems cited is lack of money. It is difficult to calculate just how much money is allotted for services for the visually impaired in Canada, but if we knew, the amount would be staggering. More money is not always the solution; rather, better planning and co-ordination of comprehensive services can achieve surprising results.

Another problem, and perhaps a more basic problem, concerns co-ordination. In many cases, people are receiving conflicting information from a variety of sources. It is not unusual for parents of a child with visual impairment to receive

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advice from 15 different sources and to be left confused and without clear direction. In other cases, people are not receiving enough information, or what they are receiving is fragmented. Or they get fed up with bureaucracy, with being shunted from one place to another. The result is often that they are trapped at a particular part of the network, labeled as blind or not blind, and not really receiving the most beneficial assistance — and CNIB must accept its share of criticism in this regard. For these reasons it is imperative that all of us work together to co-ordinate our efforts.

To return to that all-important human services aspect, it is not unusual for consumers to complain that specialists in low vision are authoritarian and unimaginative in their counselling. Consumers say that low vision experts do not tell them the things they really want to know. And perhaps worst of all, many low-

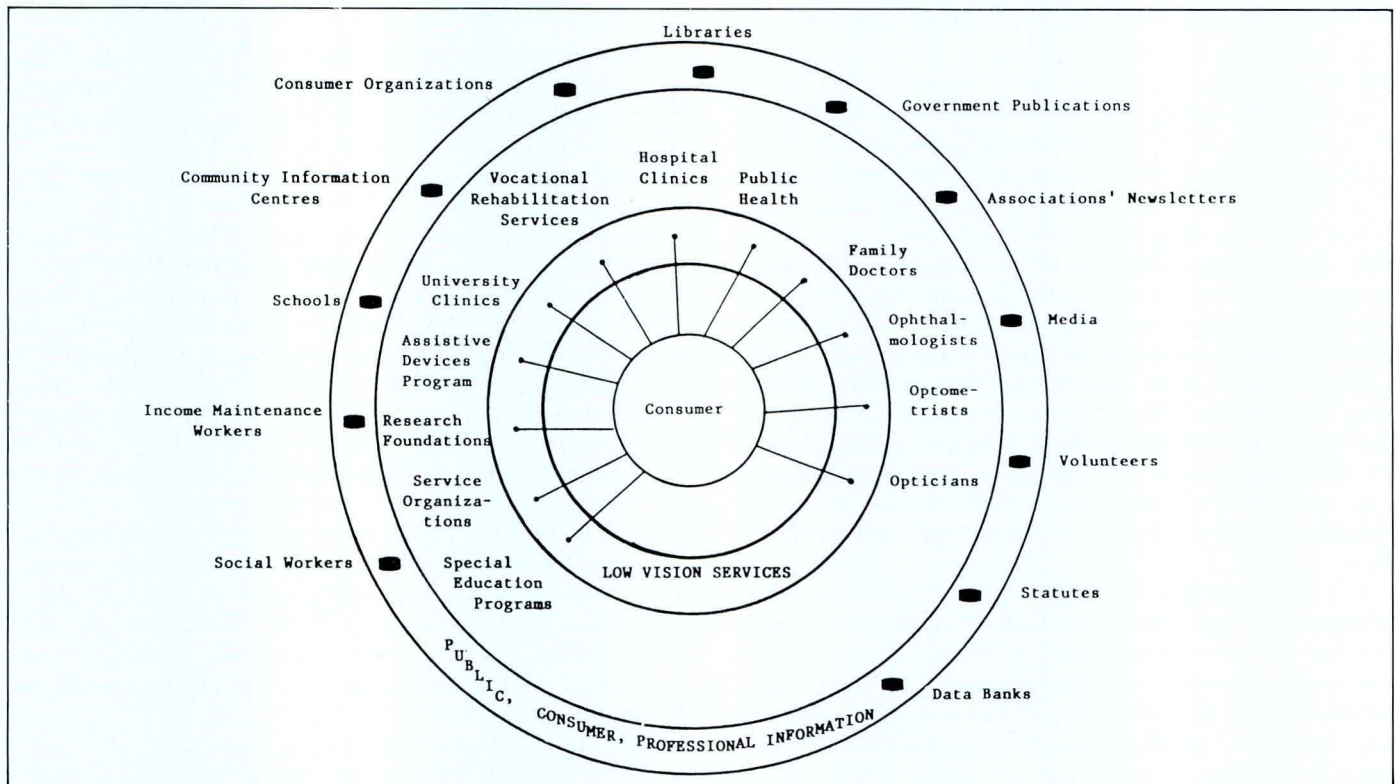


Figure 2. Low Vision Services Network



visioned people believe the experts have focused their work so narrowly on the eyes themselves, that they overlook the person in whom the eyes reside.

The answer to many of these problems is planned co-ordination of funds and services. In the absence of co-ordinated services, this incredible system functions not as the safety net it was meant to be, but as a spider's web, restraining and confusing, and preventing the individual from receiving equitable and beneficial service. With the necessary co-ordination,

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basically adequate resources in the developed world, and the potential for the establishment of adequate resources in the developing countries, we can provide the kind of safety net truly required.

Each discipline has a clear picture of what needs to be done and how it should be done. The problem arises when these disciplines become so narrowly focused on their own specific areas that they are unable to work together with others to present a clear direction to the consumer. Without the ability to see beyond their own specialties and conditions, valuable resources are wasted and effectiveness and ability to truly help people with low vision to achieve their full potential is reduced. While we have sight, we sometimes lack vision, the vision that will give us what we seek — an effective, efficient and caring sight enhancement system accessible to all.

A final word of caution — organizations of and for the blind and visually impaired risk sliding under the umbrella of the generic disability group. There is, in this worrisome trend, an inherent danger that the problems that have been identified for this group will be compounded if we water down, or worse, lose the special knowledge and expertise that is required for successful intervention.

## 2. Summary and Conclusion

This review of current and historical trends has been presented as a guide for future planning and activities. Enough is known of the future in respect of demographic, economic and technological trends to project service requirements well into the 21st century. It is clear that we must make our existing resources work more efficiently and more quickly to serve more people. We must allocate both human and financial support to make the principle of equity a reality throughout the world. In this regard, we cannot overlook the dramatic and excellent work currently underway to prevent blindness or severe visual impairment, since as much as 80 per cent of blindness is said to be preventable. Where prevention of blindness is not possible, remedial programs must be either developed or strengthened.

Relevant research and statistical data will help us all in that essential process of planning and co-ordination. As this information is studied and analyzed to determine its relevance to the respective disciplines and organizations, it should be done with a sense of excitement and renewal. This is truly a unique opportunity to challenge and be challenged. Our response must reflect our belief and resolve that the impossible can be achieved

through co-operation, planning and co-ordination. We can reduce or eliminate barriers to service, whether they be social, economic or organizational. Too long have we accepted systems established to serve humans, systems that, over time, have become inflexible and insensitive, and that in their worst applications create orphans rather than beneficiaries.

Much has been written about the incredible sight of the eagle. The vision of a clam is a frightening parody of that keen eyesight. The information reviewed in this paper suggests that, in respect of sight enhancement systems, we have a sky full of eagles with the clearest sight in their respective areas. The challenge before us is to harness those eagles and to focus their vision towards the future where the world can be relatively free of blindness and severe visual impairment. Astronauts, from their vantage point in space, have described with awe the incredible beauty of our earth. Our view of that world must be shared through a common vision of what can be achieved through our collective contribution as individuals with a common purpose.

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