

# The Needs of Older Persons with Low Vision: The Need to Respond

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## Position

This position paper describes the comprehensive service needs of older persons who have low vision. As such, it does not focus solely upon low vision needs, but instead explores the full range of vision rehabilitation service options that are available for older adults.

The personal and service needs of older people with low vision resulting from age-related vision loss are enormous. Far too little is known about vision loss and low vision by far too many people who could otherwise make a difference in the lives of older persons. It is because of the growth in the population of older persons who are visually impaired that vision loss has become a public health issue (Orr, Rogers & Scott, 2007).

Demographically, we are living in an age that is without precedent. The median age of the US population is 35.3, the highest it has ever been, and reflects a 28% increase in the number of individuals aged 35-64. In addition, the population aged 45-54 increased 49% during the past decade (US Bureau of the Census, 2000a, 2000b).

The number of persons who are 65+ increased from 25 million in 1980 to 35 million in 1990, and is projected to reach 70 million by 2030; in addition, the 85+ age group is the fastest-growing segment of America's older adult population. The number of persons aged 85+ has more than doubled since 1965, and is expected to increase from 3.8 million in 1996 to 8.5 million in 2030 (US Bureau of the Census, 2000a, 2000b).

In addition, because females have a greater life expectancy than males throughout the world, demographers are also interested in specific aging trends among **older women** (Administration on Aging, 2003, 2004):

- The average life expectancy at birth is 80 years for women and 73.5 years for men.
- Since women have a longer average life expectancy than men and also tend to marry men older than themselves, 7 out of 10 women will outlive their husbands. Many women can expect to be widows for 15 to 20 years.
- Compared with men, elderly women are:
  - 3 times more likely to be widowed or living alone;
  - 2 times more likely to reside in a nursing home;
  - 2 times more likely to have incomes below the poverty level

Closely aligned with this rapid growth in the aging population is the increased incidence of vision impairment among persons 65 and older. There are currently 6.5 million people age 65 and older who are visually impaired, and this number is expected to double by 2030 (American Foundation for the Blind, 2007a).

According to a 2007 national survey conducted by the American Foundation for the Blind, 21% of Americans believe that vision loss would have a more negative impact on their quality of life than HIV/AIDS, cancer, stroke, heart attacks/disease, diabetes, and deafness (American Foundation for the Blind, 2007b).

Some of the most critical needs related to older people with vision loss relate to medical management, particularly of diabetes, the incidence of falls, medication management, and adequate nutrition. Additional health conditions, such as arthritis, cardiovascular disease, hearing loss, Parkinson's disease, and complications from a stroke can complicate the effects of adult-onset vision loss and require specialized management, such as environmental modifications and adaptations for daily living skills, include (Duffy, 2002).

Many of these critical – and highly specialized – needs remain unaddressed, however, because of the limited access of older adults to appropriate vision-related rehabilitation services. **The lack of awareness about the availability of vision-related rehabilitation services is one of our nation's best-kept secrets.**

## Introduction

Older people who experience vision loss need not feel or be perceived as dependent, isolated, hopeless or helpless. In order to meet the complex needs of older people with low vision, vision rehabilitation professionals must recognize the need to collaborate with service providers in the aging network, the health care arena and particularly home health care. The more these professionals know about vision loss and its associated comorbidities, the more they can work with professionals in the vision field and family members to address the conditions and circumstances associated with vision loss.

The term “vision rehabilitation” includes a wide range of professional services that can restore functioning after vision loss, just as physical therapy restores function after a stroke or other injury. Vision rehabilitation services allow older adults who are blind or have low vision to continue to live independently and maintain quality of life.

Although the eye doctor is the professional whom consumers and family members turn to initially when dealing with vision loss, it's important to note that a range of vision rehabilitation services are available in addition to the eye care provided by a family doctor, ophthalmologist, or optometrist:

- Communication skills
- Counseling
- Independent living and personal management skills
- Independent movement and travel skills
- Low vision evaluations and training with low vision devices
- Training in the use of functional vision
- Support groups

## Key Points

## 1. Need to Recognize Cultural Diversity

It is important for service providers within and outside the vision field to recognize the higher incidence and higher risk factors of some of the age-related eye conditions, primarily glaucoma and diabetic retinopathy among older persons who are African American and Hispanic or Latino (NEI, 2004).

- a. Unlike younger generations of Hispanic and Latino persons who may have become acculturated to American societal customs and language, older people who do not speak English as their first language need bilingual/bicultural service providers, otherwise they may be reluctant to accept services from Anglo service providers.
- b. These circumstances speak to the critical issue of the need for bilingual and bicultural vision rehabilitation professionals to work with older minority group members who are experiencing age-related vision loss. Not only does the vision rehabilitation field experience major personnel shortages, (Orr & Huebner, 2001) particularly among vision rehabilitation therapists, it also needs to address the need for more bilingual/bicultural vision rehabilitation personnel to meet the needs of older persons in particular.

## 2. Need for Professional and Public Education

As described above, the general public and professionals across many disciplines need to know about the vision rehabilitation service delivery system available to older persons who are losing their vision.

- a. More and more private citizens are beginning to be aware of vision loss because they have an older relative with macular degeneration, glaucoma, diabetic retinopathy and complicated cataracts.
- b. Coverage of macular degeneration, for example, now makes the evening news from time to time because of the clinical trials underway to develop treatment for wet macular degeneration such as [Lucentis](#), [Macugen](#), and [Avastin](#). Awareness is raised to some degree in comparison to a decade ago, but the general public still does not know what to do. They need to know that vision-related services exist, what the eligibility criteria are, and how to access these services.
- c. Professionals in health and human services need to develop an initial knowledge base about older people with low vision and the services available to serve them.
- d. These professionals, beginning with the eye care professional, need to be an essential referral sources for older people. As difficult as it is to imagine, many eye care professionals do not make referrals to state agencies for the blind and visually impaired, and many do not make referrals to low vision specialists (Orr & Rogers, 2006), nor to vision rehabilitation service providers, as defined previously.
- e. Right now, older persons lack essential referral sources so they remain uninformed about the potential for independent and productive living.
- f. Materials have been developed to train various disciplines about this population but more collaboration and partnerships need to be developed with the aging network, the health care system and the public health arena to ensure that older visually impaired people get the services they need.
- g. Professionals need to know that there is a federal funding source available at each state agency for the blind and visually impaired called **Title VII Chapter 2 of the Rehabilitation Act (Independent Living Services for Older Individuals Who Are Blind)** that provides low vision services provided by low vision specialists, independent living skills training, provided by vision rehabilitation therapists and

orientation and mobility instruction provided by orientation and mobility therapists. (In this program, “blind” refers to all older persons experiencing vision loss. In some states it means legal blindness is required for eligibility; other states only require low vision.)

- h. **An additional potential funding source is the Medicare Low Vision Rehabilitation Demonstration Project**, sponsored by the Centers for Medicare & Medicaid Services (CMS). The purpose of this five-year demonstration project is to investigate the expansion of benefits for individuals with moderate to severe vision loss. Through this project, qualified (as defined by Medicare in terms of education and training) occupational therapists, and low vision therapists, orientation and mobility specialists, and vision rehabilitation therapists who are certified by ACVREP may provide vision rehabilitation services under the demonstration when delivering services to an eligible Medicare beneficiary under the general supervision of a qualified physician. The demonstration is, however, limited to the following areas: Atlanta, Georgia; Kansas; New Hampshire; New York City (all five boroughs); North Carolina; and Washington State.
- i. Despite these funding sources, however, coverage for vision rehabilitation services remains inconsistent and older adults who are blind or have low vision continue to require ongoing fiscal support for a wide range of low vision devices and services, including optical devices (hand-held and stand magnifiers; magnifying reading glasses; hand-held, spectacle-mounted and bioptic telescopes; telemicroscopes) and non-optical devices (absorptive sunlenses, appropriate lighting, large print reading materials, electronic video magnifiers, and adaptive daily living devices).
- j. **Low vision services are one of the best-kept secrets for older people who are visually impaired.** An eye care professional, either an ophthalmologist or optometrist, should make a referral to a low vision specialist, who may be an ophthalmologist or optometrist with specialized training in low vision. After evaluating remaining visual functioning and prescribing appropriate low vision devices, a certified LVT will instruct the older person in the use of these devices, which helps the older person make the best use of his or her remaining vision. A family member or the older person him/herself at the end of the eye care specialist’s examination should ask for a referral to a low vision specialist if one is not offered. The more family members and professionals know about this essential service, the more they can create an informed consumer so he/she can advocate for him/herself.

### **3. Need for Family Member Involvement in the Vision Rehabilitation Process of an Older Relative**

The involvement of family members in the vision rehabilitation of older relatives has changed over the decades. At earlier stages, many vision rehabilitation professionals believed that the presence of family members would result in intrusion and/or distraction during instruction, which could interfere with the learning process. Many family members felt they should speak on behalf of the older person, often to the dismay of the older consumer. When instruction was provided in the home, family members were frequently asked to leave the room.

- a. A revolution in thinking has occurred during the last decade. Many vision rehabilitation professionals believed that family members should be involved.
- b. One line of thinking is that if a family member is present and observes the instruction of adaptive skills, he/she may be able to reinforce the instruction between sessions

with the rehabilitation professional. Available family members are told that it is important to reinforce new skills.

- c. If services are provided in low vision clinics, medical offices, or community-based vision rehabilitation agencies, a key family member may be invited to participate. If services are provided in the older person's home, family members may be encouraged to be present during instruction in order to observe and reinforce the skill between sessions. This is particularly important in rural communities where as many as four weeks may pass between sessions, and the older consumer may have difficulty remembering the steps in the new adaptive technique for carrying out a task.
- d. There are a few leaders in the field of aging and vision loss who are considering and exploring whether a family member can be trained to provide basic instruction to an older relative, primarily to address the personnel shortage among VRTs and support the work of existing VRTs and enable them to serve more people. This is a revolutionary strategy for the field to explore and develop a level of comfort as to what tasks the family member may perform, such as those that do not involve safety issues, such as cooking (Orr, dissertation proposal, 2007).

#### **4. Need for Family Education and Support**

In order for family members to effectively support their older relative (or friend) throughout and after the rehabilitation process, it is important that they can take advantage of educational opportunities provided by agencies serving their older friend or relative so that they understand the functional implications of the older consumer's vision loss and so that they have some understanding of how and when to step in and provide assistance and when to let the older person work through the activity on their own. Many agencies are beginning to have open houses for family members for this kind of information exchange (Silverstone, 2002).

- a. Family members may also experience considerable concern and burden about their older relative's vision loss. They need the opportunity to meet with other family members experiencing some of the same feelings and concerns so that they know that they are not so isolated and alone in the process. Many family members struggle with when and how and if they should address the issue of their older relative's vision loss. The issues and difficulties associated with vision loss can cause family communication to breakdown and it is one of the most important elements in the successful adjustment to vision loss for the family as a unit. Support groups for family members are as important as those for the older consumers (Silverstone, 2002).

#### **5. Need for Self-Advocacy Skills Training**

Some older persons who experience age-related vision loss lose their sense of self-confidence, self-esteem and self-worth. The vision loss is experienced as disempowering for the older consumer. Without self-advocacy skills training, the older person may continue to live with feelings of lack of empowerment.

- a. Some vision rehabilitation agencies include helping the older consumer advocate for him/herself during the instruction of skills. Others do not specifically address self-advocacy skills. In the process of identifying the specific goals of a national initiative, the National Agenda on Vision and Aging, consumer representatives advocated that the first goal should be the development of a curriculum on self-advocacy skills training for older persons experiencing visual impairment (Orr, Rogers & Scott, 2006). This was a major contribution to the project and if it were not for the efforts and ideas

of leading older consumer representatives, it may not have been a prioritized goal. Currently the curriculum exists as a priced publication of AFB Press with the intention that it would be a separate element of instruction in the rehabilitation of older visually impaired persons (Orr & Rogers, 2003). No older person's vision rehabilitation program should be complete without an older person's ability to advocate for him/herself with family members, gatekeepers of entitlement services for the elderly, physicians and others. One way to address the issue is during the course of a support group (Orr & Rogers, 2001).

## **6. Need for Support Group Participation**

The best way for older consumers to resolve some of their self-conflict about their vision loss is to participate in the support group where they can experience that there are many other older persons experiencing some of the same psychosocial problems they are experiencing – feelings of being the only one with this problem, how will their friends respond to their new situation, how they can still keep up with the ongoing relationships, and how to interact effectively with their family members.

- a. They need joint activities to see how other older people are coping, how they are standing up for themselves and how they are functioning within the family unit. These experiences can help the older person experience that they are in the same position as some other older consumers, that they are way ahead of some in the adjustment process, and how they can learn from others who have made advancements that they have not made. The support group is the safe environment where they can talk about any interpersonal difficulties with family members and friends.
- b. Low vision clinics, medical offices, and community-based vision rehabilitation agencies need to recognize that the support group is an essential service and that it is one of the least expensive services to provide. Only a facilitator and volunteer transportation services are needed to make it happen. Frequently an older consumer emerges as the support group facilitator and a professional is no longer required.

## **7. Need for Productivity**

Independent living skills training is an essential part of vision rehabilitation for an older person. It is critical that the older consumer be able to continue to live as independently as possible within his/her own home and community for as long as possible. Every older consumer who meets with a vision rehabilitation professional for an initial assessment should be asked if he/she is interested in employment as a rehabilitation goal. For some older consumers, the idea of being employable is beyond their imagination and they may initially say no to vocational rehabilitation services. But during the course of gaining confidence in independent living skills training, they may realize that they would like the opportunity to enter into some level of productive activity.

- a. It is important to recognize that employment is not the only form of productive activity. Volunteerism and civic engagement are important trends in the aging arena and older people with low vision can be involved.
- b. Employment is viewed by both professionals and older consumers with low vision as the ultimate in productive activity and should not be viewed as beyond reach. Vocational rehabilitation counselors need to be educated to the fact that the older consumer is also a potential consumer of rehabilitation counseling services.
- c. As one goal of the National Agenda on Vision and Aging project, the goal 5 working group established a curriculum, *Successful Placement of an Older Consumer with a Visually Impairment: A Training Curriculum* (Rogers et al., 2001) for training

vocational rehabilitation counselors about the interest in and employment potential of older persons. The goal of the curriculum was to change their mindset and attitudes about older potential workers.

- d. Aging network employment resources, such as Title V of the Older Americans Act, need to respond to the potential older workers with vision loss may bring to the work arena.

### Summary

Both older persons with low vision and those whom they come in contact with need a solid knowledge base about some of the critical issues confronting the older person who has lived all of his/her life as a sighted person and is now newly visually impaired. More professionals need to be educated so that they can establish an effective referral base. Family members need more knowledge about what their older relative is experiencing so they can better understand how to respond in a manner that supports independent living. Older people need essential vision rehabilitation services and in many cases aging services with which they are mutual consumers so that they can overcome the psychosocial aspects of vision loss, learn independent living skills, interact effectively with those important to them, and when appropriate, engage in productive activity. It is all a matter of acquiring information about what services exist and how to access them.

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