

January 31, 2011

Re: National Eye Institute's National Plan for Eye and Vision Research

Dear Members of the Division of Extramural Research of National Eye Institute,

The American Occupational Therapy Association (AOTA) represents over 140,000 occupational therapists, occupational therapy assistants and students of occupational therapy. We appreciate the opportunity to submit comments to help shape the National Eye Institute's (NEI) "National Plan for Eye and Vision Research".

As the national association representing occupational therapy, a profession dedicated to maximizing independence and function for people across the lifespan, AOTA recommends that NEI's national plan for eye and vision research focus on clinical outcome studies, cost-benefits of interventions (including visual aids), health promotion, and prevention.

## What are the most significant scientific discoveries in vision research that have occurred since 2004?

From a rehabilitation perspective, the most significant scientific discovery has been the development of effective anti-vascular endothelial growth factor (VEGF) drug therapies to treat choroidal neovascularization in wet age-related macular degeneration (AMD). These drugs have successfully stabilized the progression of AMD and prevented the profound vision loss that significantly disables older adults with the wet form of AMD. It must be noted however that many older adults with the slowly progressing **dry form of AMD** are living longer and thus occupational therapists and other vision rehabilitation professionals are encountering increasing numbers of older adults in their late 80s to 90s with significant vision loss from dry AMD. Because of their advanced age, they also experience more comorbidities that result in activity limitations and rehabilitation professionals must be adept at addressing the needs of more medically complex patients in order to improve their skills for performing everyday activities such as bathing, dressing, cooking, and driving.

The second discovery comes from the substantial research completed as part of the NEI sponsored AREDS clinical trial showing that macular degeneration, the leading cause of low vision in older adults, is a disease of circulation with the same modifiable risk factors as those for cardiovascular disease. The finding that obesity, high cholesterol levels, physical inactivity and smoking all contribute to the development of advanced AMD supports the need for health care professionals to work with older adults with AMD to ensure that they make the necessary lifestyle changes to reduce these modifiable risk factors. Health promotion is increasingly becoming a critical component of rehabilitation. Occupational therapy practitioners encourage **health promotion** by modifying environments and tasks to ensure that persons with vision loss are able to engage in exercise, healthy meal preparation, medication management and other everyday tasks important for self-management of chronic diseases such as macular degeneration.

Another significant discovery is the correlation between activity limitations imposed by vision loss and the development of **depression**, a condition that affects nearly 2/3 of older adults with low vision (Crews et al., 2006; Jones, Rovner, Crews & Danielson, 2009) Co-existence of these two conditions in older adults with low vision can significantly impair health and participation in daily activities, which underscores the need to ensure that older adults with low vision are able to remain engaged in valued occupations and social activities to prevent depression.

What are the most significant scientific research needs, gaps, and opportunities that should be addressed by the NEI?

## **Clinical Trials: Efficacy and Effectiveness**

Despite the advancements made since 2004, older adults with low vision continue to experience significant limitations in their ability to live independently and lead productive lives. From the perspective of rehabilitation, additional research is needed to determine the most effective interventions to ensure that older adults are able to remain engaged in meaningful activities despite vision loss. Specifically clinical trials need to be conducted to study the **efficacy** of the rehabilitation interventions provided by occupational therapists, orientation and mobility specialists and other rehabilitation specialists.

**Outcome studies** examining the effectiveness of occupational therapy is urgently needed because occupational therapists have unique training and theories and are the only professionals besides ophthalmologists and optometrists covered under medical insurance for low vision therapy. Effectiveness studies need to examine if occupational therapy interventions improve daily functioning and participation across the lifespan.

Some clinical research questions include:

- Does **eccentric viewing training** (teaching people to use more peripheral retina when their central field is diseased) produce improvements in activities of daily living and instrumental activities of daily living (ADL/IADL) functioning and participation? Most studies on outcomes of eccentric viewing training do not involve occupational therapy and use reading speed as the primary outcome, rather than broader activity performance and participation, emphasized in the International Classification of Function (ICF) Model (World Health Organization).
- What is the most efficient and effective way to evaluate **binocular visual patterns**? Currently microperimetry can map out functioning retina monocularly, but therapists must use their own methods to evaluate what the patient sees functionally when both eyes are open. Ways of evaluating the binocular scotoma vary by clinic and have been developed with clinical expertise but without sufficient research data. What is the most effective way of performing this binocular scotoma evaluation?
- What is the most effective/efficient way of training patients to use their **preferred retinal locus** (PRL)? Current studies are limited in guiding practice because: (a) they do not involve occupational therapy, (b) use training methods that are not occupation-based, and (c) tend to use a "steady eye" method of training reading. The steady eye method teaches patients to read by holding their eyes steady and moving the reading material side to side in front of them. However, this compensatory approach for reading is not always applicable in performing daily activities or participating in society because so many activities (i.e. working on a computer, reading a street sign, reading a fast food restaurant menu) prevent the person from moving the material to be read; the patient must develop efficient eye movements rather than learn to hold the eye steady.

## **Self-Management Strategies and Health Promotion**

Given the increasing importance of self-management activities to reduce risk factors, research needs to focus on developing effective strategies to enable adults with age-related eye disease to make life style changes and engage in healthy behaviors to slow down the progression of vision loss. This includes examining functional **health literacy** among older adults with low vision, an area that has received virtually no research attention despite its importance to engagement in effective self-management.

Additionally, it is important to study vision loss within the greater context of aging in American society and study interventions that address the inter-relationship between **vision and other common comorbidities**:

dementia, depression, hearing loss, physical limitations from stroke, Parkinson's disease, and arthritis to enable older adults to successfully manage these chronic diseases.

## Research to Inform Policies and Reimbursement

Frequently, insurance does not cover visual aids, and yet vision is vital for driving and preventing falls. Just as a person with paraplegia needs a wheelchair to function, a person with vision loss or low vision needs visual aids to function as safely and independently as possible. We need studies to examine the effect of visual aids and vision rehabilitation on health-related quality of life.

An occupational therapist at an outpatient clinic in Michigan is unable to work with adolescents and young adults because her fiscal intermediary says there is no research showing that occupational therapy has a positive effect for this age group. We need to dialogue with CMS to plan and implement research that will inform policy-makers and reimbursement organizations.

Considering the current economic and political climate, it would be useful to have a **cost/benefit analysis** included in outcome studies. As well, cost/benefit analyses and tracking healthcare utilization would be useful to assess safety risks that occupational therapists address with older adults who have low vision, particularly medication management, diabetic care, and fall prevention.

Research has shown that improving Independent Activities of Daily Living (IADLs) with certain populations results in higher rates of independent living, greater participation in the community, and ultimately fewer health care costs.

AOTA requests that you give due consideration to these comments and incorporate them into your final plan for eye and vision research. Thank you again for the opportunity to share our expertise in the area of maximizing independence and function as it relates to research and direct care for individuals with vision loss or low vision. We look forward to working with you to implement your plan as it relates to occupational therapy research and the people we serve.

Sincerely,

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