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Visual Impairment
Charitable Trust
Aotearoa (NZ)

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SUBMISSION TO THE HEALTH COMMITTEE

in support of

Petition 2011/71

Dr Lynley Hood and Associate Professor Gordon Sanderson on behalf of the Visual Impairment Charitable Trust Aotearoa NZ [VICTA] and 1321 others respectfully request that the House of Representatives inquire into the need for accessible, comprehensive low vision rehabilitation services for the growing number of New Zealanders disabled by irreversible vision loss who do not qualify for membership of the Royal New Zealand Foundation of the Blind.

Associate Professor Gordon Sanderson and Dr Lynley Hood would welcome the opportunity to appear before the Health Committee in support of this submission.

THE AIMS OF THIS SUBMISSION ARE:

- To alert the Health Committee to the great and growing unmet need for comprehensive, accessible low vision rehabilitation services in New Zealand;
- To provide the Health Committee with background information on the issue;
- To highlight the need for the restoration of low vision clinics in New Zealand public hospitals (there used to be ten, now there are only two);
- To urge the Health Committee to do everything in its power to address the long-overdue need for accessible, comprehensive, low vision rehabilitation services in New Zealand;
- To ask that, in considering this important issue, the Health Committee invite submissions from other community and professional organisations and individuals with an interest in low vision rehabilitation.

OUR ESSENTIAL MESSAGE IS: Effective low vision rehabilitation transforms people with high support needs into independent and productive citizens.

WHAT IS LOW VISION:

Low vision is the reduced ability to carry out important life activities - such as obtaining an education, living and traveling independently, being employed and enjoying visual images - due to a visual impairment that cannot be corrected by medical or surgical treatments, ordinary glasses or contact lenses.

People with low vision are not blind. They do not need white canes, guide dogs or Braille. Given appropriate aids and education, they can successfully accomplish most tasks visually that are commonly performed non-visually by blind people.

With a few notable exceptions (e.g.in Scandinavia, and parts of Australia, Europe, the UK and North America), low vision has received very little attention by societies worldwide. In most places it has not yet been successfully integrated into healthcare, education and rehabilitation systems, nor even into public consciousness, even though the vast majority of people with visual impairments are not blind but have low vision.[1]

Like hearing loss, vision loss occurs along a continuum, but we have no everyday expression comparable to "hard of hearing" to describe the disabling effects of vision loss. Perhaps that is why, throughout New Zealand history, the focus of visual rehabilitation has been almost entirely on blindness, and the needs of the tens of thousands of New Zealanders struggling to cope with failing eyesight unaided have gone largely unrecognised, and unmet.

A GREAT AND GROWING PROBLEM:

- Over 93,000 New Zealanders are disabled by vision loss that cannot be corrected by glasses, contact lenses, medicine or surgery, and which impairs their ability to perform everyday tasks that most people take for granted such as reading, driving and shopping - but less than 12 percent of these New Zealanders are blind enough to qualify for help from the Royal NZ Foundation of the Blind.[2] For the remaining 88 percent, comprehensive, accessible, low vision rehabilitation services are scant, or non-existent.
- Low vision affects everyone from infants, to school-age children, to adults in full productivity with major family responsibilities, to energetic older folk actively engaged with their businesses, professions, families and communities.
- Currently, the most common cause of vision loss, age-related macular degeneration, is neither preventable nor curable (but early detection and appropriate treatment can prevent blindness).
- People with poor vision usually live to a normal old age. Without rehabilitation, their quality of life will fall, and their helplessness and dependency will rise.
- Irreversible vision loss is twice as common as dementia. Since sight loss escalates each decade over the age of 40, with our ageing population the problem is bound to get worse.
- Compared to their sighted peers, visually impaired people who have not received appropriate rehabilitation have a much higher risk of falls, and are much more likely to be admitted to hospital or a nursing home as a result.
- Compared to their peers with mobility, agility and hearing disabilities, people with age-related vision loss are over-represented in residential facilities (Table 1). Since many blind people live independently in their own homes, VICTA is confident that people with low vision, given appropriate aids and education, can do so too - thereby providing significant savings for our health budget.

Table 1: Percentage of New Zealanders 15 years of age and over with visual, hearing, mobility or agility disabilities living in households or residential facilities.

Disability type	% living in households	% living in residential facilities	Total
VISUAL	83	17	100
HEARING	93	7	100
MOBILITY	91	9	100
AGILITY	90	10	100

Source: Post-census disability survey, Statistics NZ 2006.

WHY WE NEED LOW VISION REHABILITATION SERVICES:

New Zealand Prime Minister Rt Hon Peter Fraser coped with low vision throughout his long political career by successfully combining the technology (pebble spectacles), techniques (large print documents held close to the face)[3] and skills (listening carefully to, and retaining, large amounts of oral information) that enable people with low vision to lead active, independent and productive lives.[4]

High quality magnifiers, large print documents and spoken information are, within the context of Vote Health, remarkably inexpensive rehabilitation tools, and, when measured against Peter Fraser's achievements, remarkably cost-effective. It is a matter of concern that more than 60 years after Fraser's death, low vision rehabilitation is unavailable to most New Zealanders who need it and could benefit from it. The failure to provide appropriate low vision services prevents many New Zealanders from achieving full social inclusion and optimal quality of life. It also increases costs to society, and deprives society of the human and economic contributions of these individuals.

WHAT LOW VISION REHABILITATION SERVICES NEED TO PROVIDE:

For the purposes of this submission we define low vision rehabilitation services as any service for improving the use of available and functional vision, recognising that these services may include, and be delivered by, a range of disciplines, organisations and informal social processes.

The goals of low vision rehabilitation are multi-faceted because low vision affects people in far-reaching ways throughout their lives. Low vision can trigger depression, unemployment or underemployment, illiteracy, and social, cultural and educational exclusion. It can result in loss of independence in travel, financial management, personal care and social interactions. It can isolate individuals and reduce their access to the practical and cultural information normally obtained by sighted people from printed material, television, the internet and other visual sources.

As well as being of the highest professional standard, low vision rehabilitation services need to be financially, geographically and culturally accessible to all New Zealanders.

Comprehensive low vision rehabilitation services need to include:

- a low vision clinic where an individual's visual ability and visual needs are professionally assessed and regularly reviewed, and where appropriate visual aids are provided from an equipment lending library.

- counselling to help people come to terms with their vision loss, to assist them in reviewing their options for the future, and to ascertain when rehabilitation can begin.
- Activities of daily living (ADL) tuition where people learn adaptive techniques for activities like home management, grooming, and cooking.
- Orientation and mobility (O&M) tuition where people learn techniques to enable them to travel safely in both familiar and unfamiliar environments.
- Eccentric viewing tuition where people who have lost their central vision learn to read using their peripheral vision.
- IT tuition where individuals are familiarised with computer programs and devices that enable people with low vision to keep in touch with their families, their friends, their communities and the wider world.
- Occupational therapy in the home environment to ensure that people are safe and can use their adaptive equipment correctly.
- Peer support groups where people with low vision can meet others facing the same challenges to share information, support and practical knowhow.

LOW VISION SERVICES CURRENTLY AVAILABLE IN NEW ZEALAND:

Despite escalating levels of age-related vision loss nationwide, low vision clinics based in public hospitals are largely a thing of the past. Clinics that used to serve the people of the Wellington, Palmerston North, Hawkes Bay, Whangarei, Gisborne, Nelson, Whanganui and Dunedin regions have been disestablished. The Dunedin service has gone from two clinics - one for adults, one for children - to none. New Zealand's only two remaining state-funded low vision clinics are in Auckland and Christchurch.

To the best of our knowledge, there are two commercial low vision clinics in New Zealand, one in Auckland, the other in Hamilton (there may be others of which we are unaware). These clinics provide optometric assessments and adaptive equipment to people who can afford the unsubsidised professional fees and the sometimes expensive low vision aids.

The Royal New Zealand Foundation of the Blind has recently completed an Auckland-based pilot scheme designed to supplement the RNZFB's income by providing a commercial service for people with low vision who are not blind enough to qualify for membership of the RNZFB.

There are many informal peer support groups scattered throughout New Zealand where people with low vision meet to pursue common interests and share information and support.

Retina NZ (a consumer group of the RNZFB) facilitates several peer support groups, and provides free printed information and an 0800 peer support line, The eye disease charities Glaucoma NZ and Macular Degeneration NZ have 0800 numbers. Sight Loss Services, an Auckland-based charity, provides free publications and speakers on low vision, and operates a commercial low vision clinic and an 0800 number. VICTA has an 0800 number, facilitates a Dunedin-based support group, and is pioneering a low vision/high visibility road safety campaign (a world first).

The problem for all these services is that, when faced with the questions uppermost in the minds of people who are losing their sight - "Where can I go in my nearest town or city to get professionally assessed for suitable low vision aids?" and "Do you have a trained professional who can advise me on what I need to do to stay safely in my own home as my sight deteriorates? - for most people in most parts of New Zealand the answer to the first question is "Nowhere", and to the second question is "No".

A FRAMEWORK FOR LOW VISION SERVICE DELIVERY

VICTA supports the WHO classification and recommendations on low vision service delivery at primary, secondary and tertiary levels as outlined in the 2004 Oslo Workshop report.[5]

In particular, VICTA endorses the need for tertiary low vision services in large hospitals. These ensure that a wide range of eye and health care providers are available for referrals and consultations. They also provide high quality clinical care, and a teaching and research environment in which national and international collaboration can thrive, where health and rehabilitation professionals in all disciplines can receive quality training, and from which low vision care and rehabilitation throughout the community can be monitored, supported and kept up to date.

VICTA also supports the Oslo proposal that low vision service delivery be coordinated with extensive public education and outreach activities, not only to ensure that more individuals with low vision have their needs met, and low vision becomes more visible and socially accepted, but also, by coordinating with employers and employment agencies, to ensure that jobs are retained and prejudice about vision loss does not prevent employment taking place.

Rather than reviewing the Oslo proposal in more detail in this submission, VICTA would welcome the opportunity to work with government agencies and other parties to plan and develop a comprehensive, accessible and effective rehabilitation service that meets the needs of all New Zealanders disabled by vision loss.

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1. Towards a Reduction in the Global Impact of Low Vision: Oslo Workshop, 2004 http://www.visualimpairment.org.nz/resources.

2. Disability Survey, Statistics NZ, 2006.

3. "Through them [pebble lenses] he [Fraser] would peer at widely spaced words printed in extra bold type and held close up to the face." Hon Dr Martyn Finlay in *Peter Fraser: Master Politician*, ed. Margaret Clark, Dunmore, 1998.

4. "[Fraser] preferred oral to written reports; he usually gave his instructions verbally and would always use the telephone in preference to writing a letter or to issuing signed instructions." Sir Alister McIntosh, 'Working with Peter Fraser: Personal Reminiscences', NZJH, 10/1/02.

5. Towards a Reduction in the Global Impact of Low Vision: Oslo Workshop, 2004 http://www.visualimpairment.org.nz/resources.