

The Standard-Bearer

APRIL 2009 INSERT ARTICLE

Standards for Blindness Prevention

J. Graham Strong, O.D., NAC Vice-President

NAC is in the throes of reviewing the relevance and evidentiary validity of current standards for accreditation for agencies and schools serving people with vision loss. A significant gap became obvious in the area of blindness prevention services, which has become an important service undertaking for many agencies seeking accreditation. The obvious complication in developing standards for blindness prevention is the amorphous scope of activities to which such standards might apply. A logical starting point was to review the published literature from various organizations that incorporate "blindness prevention" within their stated missions, aims, strategies, and objectives. Most prominent among these organizations are Prevent Blindness America (PBA) <http://www.preventblindness.org/about/>, International Agency for the Prevention of Blindness (IAPB) <http://www.iapb.org/>, VISION 2020: The Right to Sight <http://www.v2020.org/> and ORBIS International <http://www.orbis.org/>. A consistent theme within these organizations is the prevention of avoidable blindness, which primarily involves the provision of medical, optometric, and surgical interventions to mitigate vision loss from conditions such as cataract, trachoma, and uncorrected refractive error. Given the inception dates and sponsors of these various "blindness prevention" initiatives, it seems logical for them to be strongly anchored within a medical rehabilitation model. A **medical model** of disability regards disability as *"a defect or sickness which must be cured through medical intervention."* In some instances, this approach is tempered by adherence to a **rehabilitation model**. This constitutes an offshoot of the medical model, wherein disability is considered to be *"a deficiency that must be fixed by a rehabilitation professional or other helping professional"*.¹

The International Classification of Diseases (9th revision)² describes several categories of visual impairment having a "blindness" designation. Accordingly, "blindness" was historically interpreted internationally as having a corrected visual acuity of less than 3/60 in the better-seeing eye. The justification was that this level of vision loss would preclude individuals from functioning effectively within their communities.³ Over the ensuing decades, service providers and consumers became increasingly aware of the arbitrariness of this clinical definition of blindness. One significant concern was the growing number and significance of visually demanding tasks in our contemporary society (daily living, driving, orientation and mobility, reading, computing, communications, and social interactions). This concern is described as follows by West and Sommer (2001).⁴

"Population-based research has shown that at a best corrected acuity of 6/18 (20/60) or less, 85% of people aged 65 and over cannot read standard newsprint effectively (i.e. they read less than 80 words per minute) (S. West, unpublished data). Among people with a best corrected acuity less than 6/30 (20/100), 87% have significant difficulty recognizing faces. At 6/60 (20/200), over 50% of

continued on insert page 2

continued from insert page 1

people have difficulty with mobility, and over 66% have difficulty with simple tasks such as dialing a phone number, or using a key or plug correctly. For the success of communities of the future, the goal must be prevention of avoidable visual loss at these lower acuity levels in order to maintain the functional capacity and employment of affected people. "Economic" blindness might be more appropriately set at a visual acuity of less than 6/18 (20/60): this level should be used as the target for eliminating avoidable visual loss."

The *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) was developed in 1980 by the World Health Organization (WHO) as a tool for classifying the consequences of disease, injury, and disorder, and to facilitate analyses of health-related issues.⁵ When applied to blindness and low vision, these categories provide significant qualitative differentiations which are useful for postulating a generic intervention service model. The following definitions illustrate these distinctions.

A **disorder** is present whenever there is a deviation from the normal structure of the visual system. It refers specifically to any physiological or pathological anomaly affecting the eye and/or its neural connections.

Impairment refers to any measurable loss of functional capability relative to the normal variation within the population. Visual impairment therefore describes the deficient response capabilities of the visual system to perform any of the various psychophysical tests that comprise a vision assessment. These may include commonly measured functions such as visual acuities, visual fields, and colour vision, as well as less commonly measured functions such as contrast sensitivity, glare testing, or dark adaptometry. The visual impairment is delineated by the specific procedures used to measure it.

Disability describes an individual's lost capacity to undertake work in the presence of her or his impairment. A visual disability thus refers to any diminished or relinquished functional ability to perform visual tasks that are necessary to maintain one's desired lifestyle. A common disability is the inability to read standard printed material.

Handicap describes the actual or perceived social reaction to an individual's disability which arises in her or his relationship with other people. A visual handicap, therefore, consists of any economic, social, or psychological disadvantages experienced by people as a consequence of their vision loss. Physical independence, mobility, economic independence (employment) and social integration are some of the major parameters used to evaluate handicaps.

Ongoing revisions to ICIDH sought to better reflect how social, behavioral, and environmental factors impact on the concept of "*handicap*". The 2001 revision, entitled the *International Classification of Functioning, Disability and Health* (ICF), incorporates these additional considerations by classifying functioning at the level of the body/body part, the whole person, and the whole person in social context. Notwithstanding these modifications, the initial conceptual distinctions between impairment, disability and handicap remain relevant when contemplating a conceptual model for rehabilitation services.

An important function of NAC standards is to protect consumers from unsystematic or anecdote-based intervention approaches that potentially under-exploit the availability of relevant services. An important component is for service providers to be suitably well-trained and the

continued on insert page 3

services they provide must be informed by contemporary evidence of high quality. It is equally important for these services to be available at the appropriate time within an integrated consumer-centred service delivery matrix. A conceptual model allows service providers and service users to mutually appreciate the importance of proper sequencing and integration of these service offerings. The quantitative classification of deficient visual performance into low vision and blindness categories provides no useful information for developing an appropriate model for service delivery. A more useful approach is to recognize intervention strategies that are based on the classical public health concepts of disorder, impairment, disability, and handicap.

The normal range of presentations for any health status occurs as a continuum and not a dichotomy. In addition to obviously healthy and unhealthy states, there is usually an extensive range of intermediate circumstances arrayed between the two extremes. The logical implication is that, in spite of any discrete semantic distinctions which differentiate visual impairments from visual disabilities and visual handicaps, all of these various features may occur simultaneously to a greater or lesser extent whenever a vision disorder occurs. Anyone with a vision disorder may have consequent visual impairments, disabilities, or handicaps. Successful intervention and prevention strategies anticipate this potential aggregation and provide the appropriate investigative and remedial services to methodically identify and sequentially address each and every aspect of the individual's problem. It is illogical, for example, to invoke device assisted rehabilitation before confirming that medical or surgical intervention cannot solve the problems being reported. Another important requisite is that neither success nor failure to prevent one aspect of the overall problem can be allowed to preclude or curtail the successive investigation and attempted remediation of the other subsequent dimensions which may persist. It is inappropriate to dismiss vision rehabilitation as an option whenever medical and surgical intervention fails.

The World Health Organization (WHO) has consistently advocated services for people with vision loss that strive toward the prevention of disabilities as well as the rehabilitation and integration of affected individuals into normal society with the highest obtainable level of functioning and independence. The realization of these objectives is highly dependent upon multidisciplinary cooperation and teamwork. Although these precepts are supported in principle by most service providers, individual professions may inappropriately view their professional participation to be the key ingredient within the overall service delivery matrix. This partiality may compromise the ultimate effectiveness of any preventive rehabilitation approach if the emphasis and scope of any ensuing services become insensitive to the genuine needs of individual service consumers. It also may foster a service environment wherein some appropriate follow-up or referral procedures are suppressed or curtailed when they are not available within the facilities of the initial service provider.

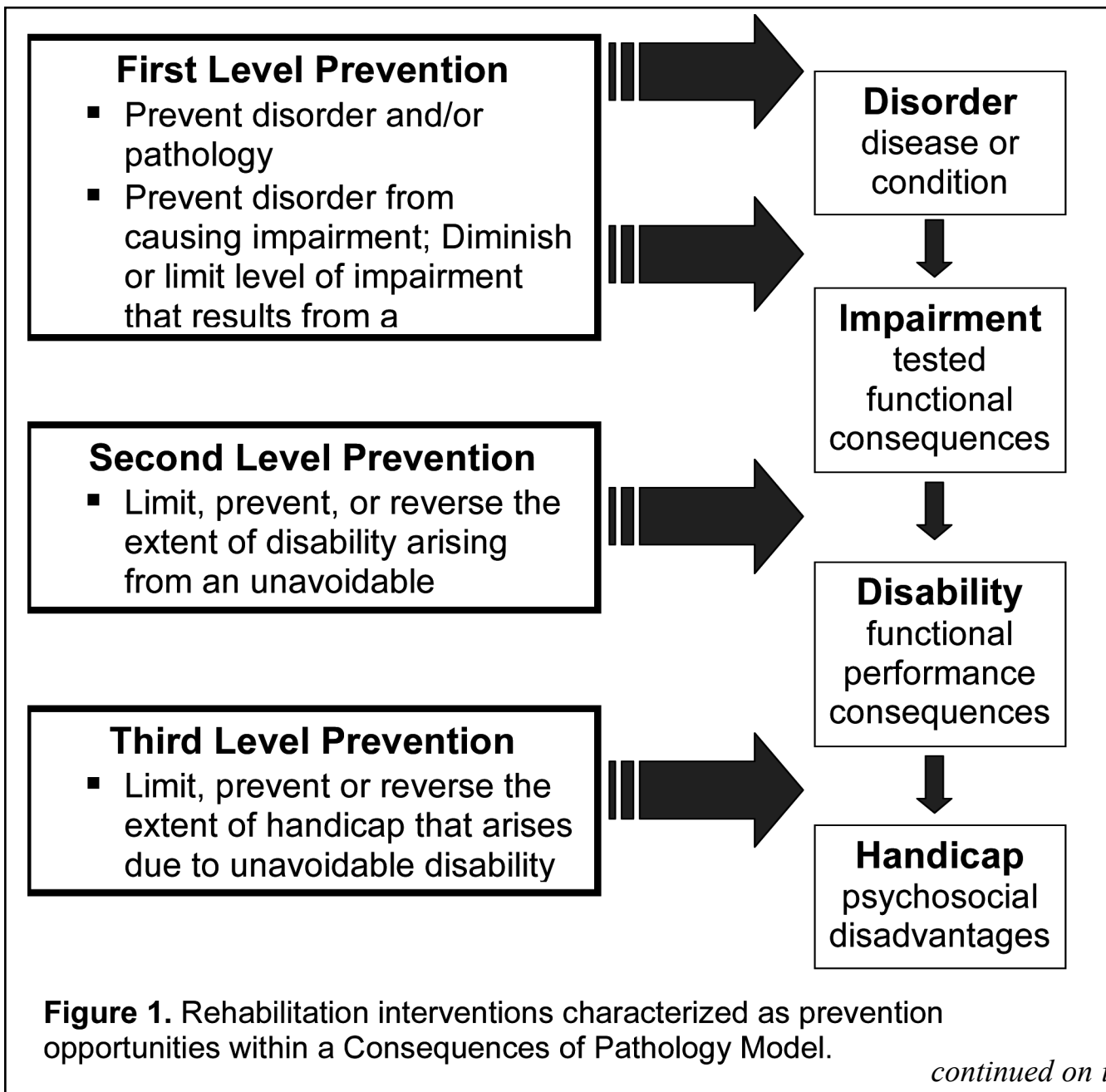
This semantic hierarchy that differentiates the ensuing impairments, disabilities and handicaps as a consequence of disorders (disease or conditions affecting the eyes and/or their neural pathways) fostered a concordant stratification of prevention into primary, secondary, and tertiary levels within a Model of Consequences of Pathology. Within this consequence of pathology model, there are three obvious opportunities for prevention services and/or activities. In addition to the traditional notion of preventing avoidable blindness (wherein the term "avoidable" encompasses preventable and treatable causes of vision loss), there are subsequent opportunities to prevent

"avoidable disabilities" and "avoidable handicaps" through the judicious rehabilitation services. The WHO Expert Committee on Disability Prevention and Rehabilitation (1981) identified the following three levels of prevention.⁶

* **First level prevention** - "This term is more or less equivalent to primary intervention. It includes measures aimed at reducing the occurrence of impairment". (Impairment prevention --- Prevent disorder and/or pathology; prevent disorder from causing impairment; limit level of impairment that results from a disorder/pathology).

* **Second level prevention.** - "This term is more or less equivalent to secondary intervention. Once the impairment has occurred, measures can be taken to prevent the development of disability." (Disability prevention --Prevent or limit extent of disability arising from an unavoidable impairment).

* **Third level prevention** - "Once a disability has occurred and is found to be irreversible; measures can be taken to prevent its transition into a handicap." (Handicap prevention -- Prevent or limit the

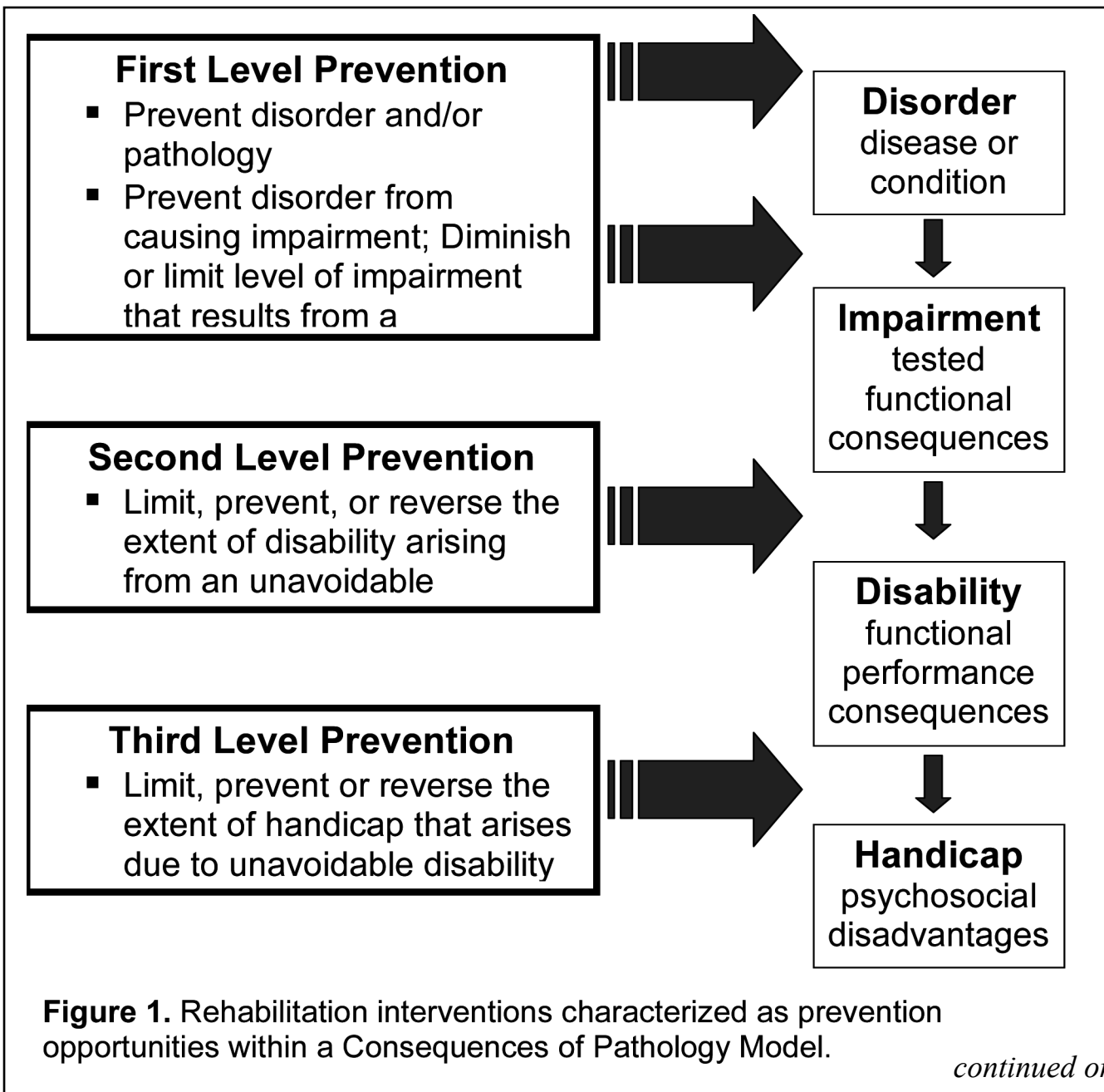


extent of handicap that arises due to unavoidable disability).

This prevention hierarchy is described in several other WHO documents, but it hasn't been prominent in any recent publications.^{7,8} These interrelationships are illustrated in Figure 1.

The utility of this model for vision rehabilitation is described in the public health and vision rehabilitation literature. Strong et al (1988)⁹ and Massof et al (1995)¹⁰ and describe how the appropriate sequencing of intervention services are anticipated within this model. See Fig. 2 & 3.

The indispensable first step consists of a thorough clinical investigation of the causal visual disorder or condition. This service is traditionally provided by surgical, medical, or optometric personnel whose intention is to determine the amenability of the disorder to conventional treatment. Any related treatment constitutes a "first level" prevention activity. The severity and impact of most visual disorders is frequently expressed using standard clinical measurements of visual impairment such as visual acuity reduction or visual field defects. The extent to which any measurable visual impairment persists following therapy describes the success of this intervention. This residual impairment may conceivably translate into a visual disability.



When a visual disability or functional decrement is identified, a problem-oriented low vision assessment is warranted. This service is routinely provided by "low vision clinicians" (optometrists or ophthalmologists with specific expertise in low vision care). Well documented investigative protocols have been established for these services which are independent of the provider's background discipline. The process consists of initially identifying and describing any outstanding visual disabilities through an extensive case history investigation followed by a low vision examination. This examination attempts to expose and quantify all manifest or hidden visual impairments that contribute to the reported disabilities. Low vision intervention may consist of recommending suitable task alterations or prescribing assistive devices. These assistive devices may be optical systems, such as telescopes and microscopes, or non optical aids, such as reading stands, boldly lined paper or signature guides. The low vision approach is geared toward lessening the functional impact of the visual impairment to such a level that the ensuing disabilities are significantly reduced or eliminated altogether.

The persistence of any residual disability after low vision therapy often results in a visual handicap requiring various levels of rehabilitative service. These services may be provided individually or jointly by peripatologists, psychologists, orientation and mobility instructors, educators, vocational rehabilitation counsellors, and other rehabilitation specialists. Their overall objective is to alleviate visual handicaps by minimizing or eliminating any negative social or economic impact arising from the persisting disability. This corresponds to "third level" prevention.

The classical qualitative differentiation between disorders, impairments, disabilities, and handicaps provides a systematic basis for determining the essential service components within a low vision service delivery matrix. The three corresponding levels of prevention constitute logical categorizations of response activities to each sequential modality. This intervention framework allows advocates, consumers, and providers to visualize the legitimate sequence and purview of each service component. Ultimately this knowledge translates into more comprehensive, better coordinated and more harmonious rehabilitation services for people with vision loss, which is wholly consistent with the original prevention objectives proposed by the World Health Organization.

Mindful of the various precedents and different perceptions concerning "Blindness Prevention", NAC recognizes that it goes well beyond simply preventing avoidable blindness through medical and health services intervention. More appropriately, the concern extends to the prevention of avoidable conditions of blindness and low vision AND the prevention of the impacts of unavoidable blindness and low vision on the people being served by NAC's constituent agencies and services. Although these latter prevention activities are described in many "blindness prevention" plans, they are often overshadowed by the prominence of primary prevention strategies that focus on medical and surgical interventions. This may reflect transition from a medical model to a social model of rehabilitation. The medical model is *"based on a narrow range of views and practices involving health and welfare"*, whereas the social model is *"based on knowledge of the experience, views and practices of people with disabilities"*.¹¹ NAC already has highly evolved standards that speak to secondary and tertiary prevention activities (disability and handicap prevention), albeit not characterized in these terms. The immediate need was to develop a standard

for primary prevention activities (disorders and impairment prevention). With this in mind, NAC has drafted a new Blindness Prevention standard to supplement existing standards within its rehabilitation standards cluster. In accordance with established policy and precedent, this evidence-informed standard will continue to evolve with input from all stakeholders (consumers, advocates, service providers, and administrators). Continuous quality improvement (CQI) strategies are used to make systematic improvements to the processes of care and service delivery embodied in the standards. This includes ongoing involvement with stakeholders and routine solicitations for feedback that is relevant to the standards themselves and to the associated review processes involved in the adjudication of NAC accreditation status.

It is heartening to note that NAC's re-characterization of low vision and blindness intervention services within a prevention framework is fully consistent with contemporary public health policies. The U.S. Department of Health and Human Services (HHS) has released a comprehensive set of national public health objectives grounded in the notion that setting objectives and providing benchmarks to track and monitor progress can motivate, guide, and focus action. The primary goal of Healthy People 2020 is to eliminate preventable disability, impairment and handicap. A feedback loop of intervention, assessment, and dissemination of evidence and best practices would enable achievement of Healthy People 2020 goals.

Graham Strong is an Optometry Professor at the University of Waterloo in Ontario, Canada. He is a former Director and Associate Dean of Science for Optometry and has served as the Waterloo's Director of the NAC-accredited Centre for Sight Enhancement (CSE) since 1987. The CSE is an internationally acclaimed low vision research and clinical facility. Strong has been an active low vision clinician for thirty-six years. His research has culminated in the development and commercialization of a procession of award-winning vision rehabilitation products. He is consulted frequently for custom device interventions designs and for unusual impairment or disability presentations. In addition, Strong is a court-recognized Forensic Optometrist who has been actively involved in numerous homicide investigations and prosecutions. Graham Strong currently serves as Vice President of the Board of Directors of NAC.

1. The Definition of Disability by Deborah Kaplan, Director of the World Institute on Disability. The Center for an Accessible Society website. Accessible on-line at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm#statexperts>
2. International Classification of Diseases, Ninth Revision, Clinical Modification. Washington, DC: Public Health Service, US Dept of Health and Human Services; 1988.
3. Guidelines for programmes for the prevention of blindness. Geneva, World Health Organization, 1979: 9-47.
4. West S and Sommer A (2001) Prevention of blindness and priorities for the future. Bulletin of the World Health Organization. 79(3):244-248. Accessed on-line on November 29, 2008 at [http://whqlibdoc.who.int/bulletin/2001/issue3/79\(3\)244-248.pdf](http://whqlibdoc.who.int/bulletin/2001/issue3/79(3)244-248.pdf)
5. International classification of impairments, disabilities and handicaps: a manual of classification relating to the consequences of disease. Geneva, World Health Organization, 1980.

6. Disability prevention and rehabilitation: Report of the WHO Expert Committee on Disability Prevention and Rehabilitation. Geneva, February 17-23, 1981. Accessed on-line on November 29, 2008 at http://whqlibdoc.who.int/trs/WHO_TRS_668.pdf
7. Gilbert C and Foster A (2001) Childhood blindness in the context of VISION 2020 -The Right to Sight. Bulletin of the World Health Organization 79(3): 227-232. Accessed on-line on November 29, 2008 at [http://whqlibdoc.who.int/bulletin/2001/issue3/79\(3\)227-232.pdf](http://whqlibdoc.who.int/bulletin/2001/issue3/79(3)227-232.pdf)
8. The health of young people: A challenge and a promise. World Health Organization. Geneva. 1993. Accessed on-line November 29, 2008 at http://whqlibdoc.who.int/publications/1993/9241561548_eng.pdf
9. Strong JG, Pace RJ, and Plotkin AD. 1988. Low vision services: a model for sequential intervention and rehabilitation. Canadian Journal of Public Health. 79 (S50 - S54).
10. Massof RW, Dagnelie G, Deremeik JT, DeRose JL, Alibhai SS, and Glasner NM (1995) Low Vision Rehabilitation in the U.S. Healthcare System. Journal of Vision Rehabilitation, 9(3):3-31.
11. Seelman K (2004) Trends in Rehabilitation and Disability: Transition from a Medical Model to an Integrative Model Disability World. Issue #22: (January-March). Accessed on-line at http://www.disabilityworld.org/01-03_04/access/rehabtrends1.shtml

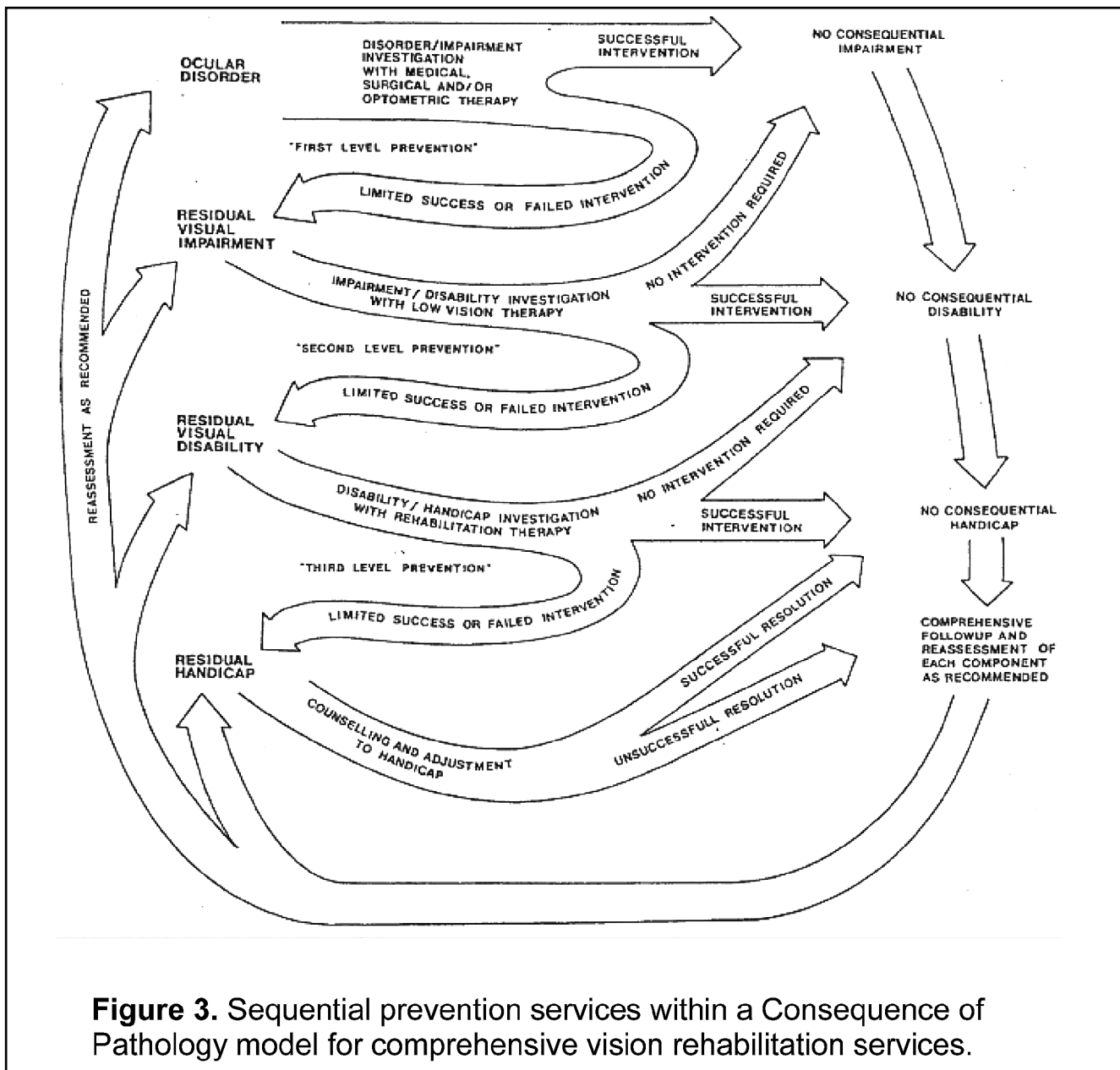


Figure 3. Sequential prevention services within a Consequence of Pathology model for comprehensive vision rehabilitation services.